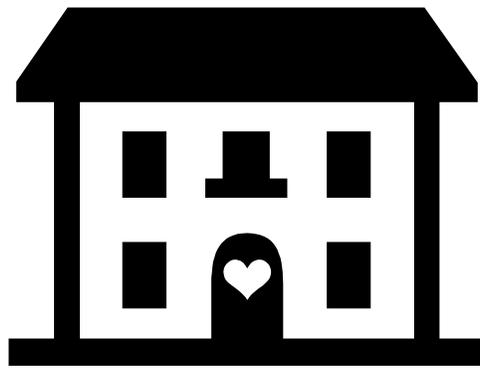


Serving The Memory-Impaired Resident In Senior Housing

A Guidebook For Staff



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Table of Contents

Chapter 1: Introduction—Audience & Assumptions Page 1

- Intended Audience For This Book1
- Assumptions: Independent Housing2
- Resources and Further Reading3

Chapter 2: Frequently Asked Questions About Memory Loss, etc.4

- What Should I Do If A Resident Seems Confused Or Behaves In A Bizarre Way?4
- Doesn't Everyone Forget?5
- When Is Memory Loss A Problem?.....5
- What Are Some Observable Warning Signs That A Resident May Be Experiencing Dementia?6
- What Causes Dementia?7
- Can Some Causes of Dementia Be Treated?8
- What Is Alzheimer's Disease?8
- Isn't Memory Loss A Normal Part Of Aging?8
- What Is The Difference Between Alzheimer's Disease And Normal Age-Related Memory Difficulties?.....9
- Do People With Alzheimer's Disease All Have The Same Symptoms?10
- What Happens As The Disease Progresses?.....10
- Is There A Violent Stage?.....11
- Why Do Symptoms Seem To Come And Go?12
- Can People With Alzheimer's Disease Live Alone?12
- When Is It No Longer Safe For A Resident With Alzheimer's To Live Alone?.....12
- I Don't Want The Resident To Be Evicted.....13
- Resources And Further Reading14
- Appendices:
 1. Steps To Getting A Diagnosis.....15
 2. Alzheimer's Evaluation Programs17
 3. Visiting The Doctor: Tips For Getting The Resident To Go20
 4. Reversible Dementias22
 5. The Three D's: Delirium, Depression and Dementia23
 6. Medications That Cause Cognitive Changes In The Elderly24
 7. Alzheimer's Disease and Related Dementias26
 8. Facts And Statistics.....29
 9. Is It Alzheimer's?: Ten Early Warning Signs.....32
 10. Stages of Alzheimer's Disease.....34
 11. Drug Fact Sheet: Cognex35
 12. Drug Fact Sheet: Aricept37
 13. Drug Fact Sheet: Exelon39

14. Drug Fact Sheet: Reminyl.....	42
-----------------------------------	----

Chapter 3: Guidelines For Communication 44

• Changes In Communication.....	44
• Actions Speak Louder Than Words.....	45
• Helping The Resident Communicate: Your Approach To Listening	45
• Your Approach To Communication	46
• Resources And Further Reading	49
• Appendices	
1. Communication Guidelines	50

Chapter 4: Dealing With Challenging Behaviors..... 51

• Five General Principals About Behavior	51
• Behaviors Common To Dementia	52
• Possible Triggers For Challenging Behaviors	53
• Problem Solving Strategies.....	54
• Tips For Responding To The Resident	56
• Strategies For Specific Behaviors.....	57
• Resources And Further Reading	58
• Appendices:	
1. Just The Facts: Bathing.....	59
2. Just The Facts: Combativeness	62
3. Just The Facts: Hallucinations	65
4. Just The Facts: Coping With Suspicion And Paranoia	68
5. Just The Facts: Incontinence.....	70
6. Just The Facts: Sundowning and Shadowing.....	73

Chapter 5: Safety Issues And Tips 76

• Why Is Safety A Concern?	76
• Observable Signs That Safety Is Becoming A Problem	76
• Possible Solutions	77
• Tips For Creating A Safe And Supportive Environment.....	78
• Wandering.....	79
• Driving	79
• Resources And Further Reading	81
• Appendices:	
1. Just The Facts: Medication	82
2. Just The Facts: Nutrition.....	85
3. Home Safety Checklist	88
4. Wandering: Plan Ahead Because It Happens More Often Than You Think	90
5. Safe Return Registration Materials	96
6. DMV: Driver Medical Evaluation	97
7. Sample Letter To Report An Unsafe Driver	98

Chapter 6: Dealing With The Situation.....	100
• Dementia In Housing	100
• The Role Of The Resident Service Coordinator	100
• Handling Specific Situations	102
• Emergency Incident, Scenario And Flowchart	102
• Non-Emergency Incident With And Without Release Of Information, Scenario and Flowchart.....	105
• Dealing With Neighbors	108
• Caregiver Stress	108
• Dealing With The Family	109
• Resources And Further Reading	110
• Appendices:	
1. Release Of Information.....	111
2. Incident Report.....	112
3. Lease Violation Letter.....	113
4. Service Coordinator Referral Form	115
5. How To Get Help For Elderly Residents Who Violate The Lease.....	119
6. Making The Decision: When Is The Right Time For Facility Care?	121
Chapter 7: Involving The Police And Adult Protective Services.....	123
• Police/Fire/Rescue	123
• Adult Protective Services.....	123
• Talking To Older Victims Of Domestic Violence	125
• Intervention	126
• Resources And Further Reading	128
Chapter 8: Legal And Financial Issues	129
• Advance Directives.....	129
• Durable Power Of Attorney	129
• Guardianship and Conservatorship.....	132
• Your Role In Guarding Decision-Making Arrangements.....	135
• Understanding The Law To Avoid Negligence Liability	136
• Conclusion	139
• Resources And Further Reading	140
Chapter 9: Creating A More Dementia-Friendly Environment.....	141
• General Principles Of Good Design For Older Persons	141
• Additional Environmental Design Tips For Dementia	142
• Resources And Further Reading	144

Chapter 10: Community Resources	145
• National Alzheimer’s Association	145
• Maine Alzheimer’s Association.....	145
• Our Services And Programs.....	146
• Maine Alzheimer’s Association Staff.....	148
• Appendices:	
1. Statewide Services	149
2. Area Agencies On Aging	152
3. Alzheimer’s Evaluation Programs	153
4. Community Action Programs	154
5. Bureau Of Family Independence	156
6. Helpful Books	158
7. Websites.....	160

About The Maine Alzheimer's Association

Our Mission

The mission of the Maine Alzheimer's Association is to serve as a resource to the community and to provide information and services to persons with Alzheimer's disease, as well as their families and caregivers. We also aim to educate the public and health care professionals about Alzheimer's disease; to advocate on behalf of people with Alzheimer's disease in policy-making arenas; and to support research into the treatment, cure, cause and prevention of the disease.

Programs and Services

We estimate that there are approximately 30,000 families in Maine who are directly affected by Alzheimer's disease or a related dementia. What follows is a list of the programs and services we provide to support those families, their friends, and health care providers. For a more complete description of these programs and services, please see pages 149–151 in Chapter 10.

- Statewide Toll-Free Helpline
- Support Groups
- Family Connections Programs
- Advocacy and Public Policy
- Education and Training
- Community Outreach Programs
- Statewide Resource Directory
- Safe Return Identification Program
- Newsletter
- Research

A Special Note To Housing Staff

The materials in this book have been specially compiled for the many professionals who provide housing and housing-related services to the elderly in Maine. If you have comments about the *Guidebook*, or would like further information, we would like to hear from you. Please feel free to call the Maine Alzheimer's Association any time at 1-800-660-2871 during regular business hours. *Thank you.*

Chapter 2

Frequently Asked Questions About Memory Loss, Dementia and Alzheimer's Disease

Neighbors complain that a resident wanders up and down the hallway, trying her key in several doors before finally finding the door to her own apartment

A normally well-groomed resident is neglecting his personal hygiene and sometimes wears multiple layers of clothing. . . .

A resident accuses people of stealing his keys or moving his apartment so that he can't find it. . . .

Q: What Should I Do If A Resident Seems Confused Or Behaves In A Bizarre Way?

A. The memory loss, confusion, and disorientation described in the above examples are symptoms of dementing illness, the most common of which is Alzheimer's disease.

Unfortunately, many people fail to recognize that these symptoms indicate something is wrong. They may mistakenly assume that such behavior is a normal part of the aging process; it isn't. Or, symptoms may develop gradually and go unnoticed for a long time. Sometimes people refuse to act even when they know something's wrong.

It is important to arrange for a physician evaluation when you recognize these symptoms in a resident. Only a physician can properly diagnose the person's condition, and sometimes symptoms are the result of treatable conditions. Even when the diagnosis is Alzheimer's disease, help is available to support and care for the person with dementia and to provide education and respite for families and neighbors.

The remainder of the Guidebook contains additional information about Alzheimer's disease and related dementias and tips for dealing with the specific challenges.

Q. Doesn't Everyone Forget?

A. Yes. Forgetting is normal, even necessary. Our brain selectively processes information, choosing to store only a small fraction of the many thousands of bits of sensory data that come our way. We can't remember every single thing that we see, hear, smell, touch, think, and feel every day, nor would we want to. And, even those things that we expect to remember, we sometimes forget. The most common memory complaints include forgetting where we put things like keys and eyeglasses, and forgetting names. Emotional problems, physical illness, and stress can play havoc with anyone's memory, young or old.¹

Memory Squashers

- **Illness, stress or worry**
- **Grief** (a significant loss such as the death of a spouse or relocation to an unfamiliar environment)
- **Inattention** (if we don't pay attention to an event or a fact it is never stored in the first place)
- **Distractions**
- **Vision or hearing loss** (we have to first be able to record information through our senses in order to remember it later)

Q. When Is Memory Loss A Problem?

A. Sometimes memory loss is more serious than ordinary forgetfulness. Diagnosis and treatment are necessary when:

- It occurs with increasing frequency;
- It interferes with everyday activities and social relationships;
- It affects other intellectual functions such as reasoning and judgment.

This type of memory loss is described as **dementia**. Dementia is an umbrella term for a wide variety of medical conditions that cause a decline in mental functioning

that is severe enough to interfere with person's ability to act independently and perform routine activities.

Q. What Are Some Observable Warning Signs That A Resident May Be Experiencing Dementia?

A. There are ten warning signs to watch for, which alone or in combination may indicate that a resident has dementia.²

1. Memory loss

- Forgets appointments or shows up over and over again at the wrong times.

2. Difficulty performing familiar tasks

- Repeated fire safety issues: burning pans, setting off smoke alarms
- Gets locked out of the building or can't find the right apartment
- Has problems with driving, such as: repeated fender benders; can't find car in the parking lot; tries key in other cars; gets lost in familiar surroundings.

3. Problems with language

- Asks the same question or tells the same story over and over
- Forgets simple words or substitutes inappropriate words when speaking
- Ignores non-compliance or eviction notices (may be having trouble comprehending written or spoken communication).

4. Disorientation to time and place

- Has trouble finding the right apartment, repeatedly tries to open the wrong door
- Wanders uninvited into other people's apartments when doors to the hallway are left open
- Repeatedly loses apartment keys or insists that the "key doesn't work."
- Gets off the elevator on the wrong floor or wanders aimlessly through the building
- Becomes disoriented in own apartment and is unable to locate the bathroom or bedroom
- Gets lost away from home and is frequently returned to the residence by police.

5. Poor or decreased judgment

- Dresses in layers or in attire that is inappropriate for the weather
- Is frequently found outside the building dressed inappropriately; e.g., in nightclothes or without a coat in the winter.

6. Problems with abstract thinking

- Fails to pay bills, or over-pays rent or other bills.

7. Misplacing things

- Throws odd or inappropriate items (e.g., full cans of food) in the trash.

8. Changes in mood or behavior

- Shows decreased attention to hygiene and grooming
- Increasing complaints from neighbors that the resident follows others, mistakes others' apartments as his or her own, or leaves the lights and TV on all night.

9. Changes in personality

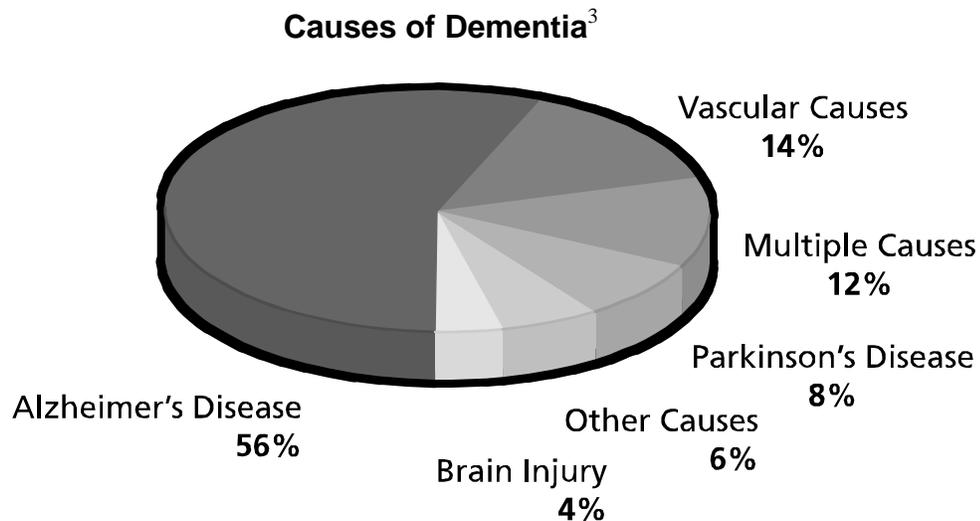
- Seems withdrawn or angry, although previously friendly and outgoing
- Makes false accusations that others are stealing personal items
- Complains that people are "changing locks," "moving my apartment and not telling me," or "hiding my car."

10. Loss of initiative

- Sits in community room all day; doesn't seem to know where to go
- Refuses to attend community gatherings, especially those previously enjoyed.
- Unsure of how to find previously familiar places, or is afraid of getting lost on the way home
- Looks to others for cues of where to go or follows other people without being invited to do so.

Q. What Causes Dementia?

A. There are at least 84 different medical conditions that cause dementia-like symptoms. **Alzheimer's disease is the most common cause, accounting for 56% of all cases, but it is not the only cause.** Other diseases, such as strokes and Parkinson's disease, may cause dementia. Other conditions such as infections or medication reactions are temporary, even reversible. Anyone experiencing memory deficits or confusion needs to see a doctor for a thorough diagnostic work-up.



Source: *An Overview of Alzheimer's Disease and Related Dementias*, Alzheimer's Disease and Related Disorders Association, Inc., 1997.

Q. Can Some Causes Of Dementia Be Treated?

A. Yes. Here are some causes of dementia that can be treated:

- Depression
- Delirium
- Medication reactions or interactions
- Thyroid imbalance
- Infections (urinary tract, upper respiratory)
- Dehydration
- Malnutrition

Delirium Requires Emergency Treatment

Delirium is an acute state of confusion that is typically triggered by an underlying problem such as hypoglycemia, infection, trauma, pneumonia, drug toxicity, shock, dehydration, CVA (stroke) or cerebral tumor. Hallmarks of delirium are rapid decline in cognitive function, disorientation to place and time, decreased attention span, poor recent memory and immediate recall, poor judgment, restlessness, altered level of consciousness, suspiciousness, and altered perception (hallucinations and delusions). A person suffering from delirium needs emergency medical care.

Source: *Nursing 1999*, Springhouse Corp., January, 1999.

Q. What Is Alzheimer's Disease?

A. Alzheimer's disease is the most common form of dementia. It affects 4 million Americans, nearly 30,000 of whom live in Maine. It is a progressive, degenerative disease of the brain in which brain cells die and are not replaced. The disease, which begins gradually and lasts from 3 to 20 years, results in impaired memory, thinking, and behavior. Eventually the person becomes unable to live independently. The average duration of the disease is eight years, but it is always fatal. As of this time, the causes are still unknown, and there is no cure. Four drugs are currently available to treat symptoms: Cognex, Aricept, Exelon, and Reminyl. [See pages 35-42 for drug fact sheets.]

Q. Isn't Memory Loss A Normal Part Of Aging?

A. Yes and no. Some thirty-year-olds have poor memories while some ninety-year-olds don't seem to forget a thing. In general, however, as people age they often

complain that their memories are not quite as sharp as they used to be. It may take longer for them to learn new information and it may be more difficult for them to recall information they already know. Compensating for these types of memory problems is easy because judgment and reasoning remain intact. People with age-related memory loss can still follow written or spoken directions. They ask for directions if they get lost or look outside to see if their clothing is appropriate for the weather. As we age, we may forget parts of an experience, but not the whole thing; we may forget what we had for lunch, but not whether we had lunch at all.

In short, although inconvenient, age-related memory loss has very little impact on a person's ability to function and it does not get worse over time. Alzheimer's disease does get progressively worse over time until it becomes impossible for the person to function without help.⁴

Q. What Is The Difference Between Alzheimer's Disease And Age-Related Memory Difficulties?

A. The symptoms of Alzheimer's disease are much more severe than simple memory lapses. Alzheimer's symptoms will eventually affect a person's work and social life and ability to live independently. The chart below shows the differences between Alzheimer's disease and age-related memory problems. **Note:** Only a physician or trained health care professional can make a determination of whether memory loss is due to Alzheimer's disease.

Activity	A Person With Alzheimer's Disease	A Person With Age-Related Memory Problems
Memory lapses	Forgets whole experiences	Forgets parts of experiences
Remembers later	Rarely	Often
Can follow written or spoken directions	Gradually unable	Usually able
Can use notes	Gradually unable	Usually able
Can care for self	Gradually unable	Usually able

Source: *An Overview of Alzheimer's Disease and Related Dementias*, Alzheimer's Disease and Related Disorders Association, 1997. (Derived from the book *Care of Alzheimer's Patients: A Manual for Nursing Home Staff*, by Lisa P. Gwyther, A.C.S.W.)

Q. Do All People With Alzheimer’s Disease Have The Same Symptoms?

A. No, Alzheimer’s disease is a variable disease, with individuals progressing at different rates and displaying widely different patterns of potential symptoms. Although all persons with Alzheimer’s disease will experience worsening problems with memory, judgment, language and motor skills, the rate of decline will vary from person to person. Other symptoms such as sleep disturbances, paranoia and agitation are behavioral in nature and may or may not be part of an individual person’s disease profile.

Q. What Happens As The Disease Progresses?

A. The disease process may begin in the brain as much as 20 years before the symptoms of Alzheimer’s appear. In general, there are three stages to the progression of the disease, which are outlined below.⁵

Early Symptoms. Stage One usually lasts between two and four years. Because the disease develops gradually, people often are able to hide their symptoms for some time. They also have good days or parts of days when they look and act like their old selves. For these reasons it may be several years before family members realize there is a serious problem and seek diagnosis. People with Alzheimer’s may refuse to see a physician, denying there is a problem. In addition, people in the early stages of the disease may:

- Forget recent events (a telephone call or meal)
- Have trouble doing arithmetic, handling money, making change
- Suddenly dislike familiar people or show less understanding of others
- Have trouble finding the words they want in conversation, frequently substituting general words or incorrect words that sound similar
- Get lost going to familiar places, such as specific locations within the housing project
- Forget how things work (the washing machine or microwave)
- Ask repetitive questions
- Lose, misplace, or hide things
- Constantly check locks, calendar, doors
- Become confused about time or abstract concepts such as “in a minute.”

Middle-Stage Symptoms. Stage Two can last from two to ten years, and is characterized by increasing memory loss and confusion. All the symptoms of Stage One become worse and the person needs increased assistance. People in the Stage Two may:

- Show changes in behavior, sleep patterns, and judgment of safety risks
- Mix up the identity of past and present acquaintances and family members
- Have trouble keeping a thought and talk in circles
- Have trouble with home safety or staying alone due to poor judgment

- Hoard things
- Urinate in strange places
- Make repetitive statements
- Follow people
- Become restless (especially in the late afternoon and early evening) and pace, get agitated or angry
- Be unable to organize, plan ahead, or follow logic
- Make up stories to fill in memory gaps
- Be unable to follow written signs or write checks
- Be suspicious, curse, fidget, or behave inappropriately
- Sit and stare for hours, forget to eat or use utensils, or eat only sweets
- Become sloppy or tactless
- Resist bathing and dressing
- See or hear things that aren't there or believe things that aren't true
- Wander in search of an old job or long-deceased parents
- Walk more slowly, and shuffle instead of picking up feet to walk
- Need help finding the toilet, using the shower, fixing food, and remembering to drink, change clothes, or dress appropriately for the weather
- Talk to their reflections in the mirror or believe television stories are happening to them
- Forget what is private behavior (may disrobe or masturbate in public).

Late or Terminal Stage. Stage Three may last from one to three years or longer. The individual becomes completely dependent on others for his or her daily needs and care. People in the late stages of Alzheimer's may:

- Fail to recognize themselves or their families, though their eyes may light up and they may have moments of recognition
- Speak gibberish, stop speaking, or become impossible to understand
- Lose control of their bladders and then bowels
- Lose weight and become unsteady or unable to walk
- Have increased risk for seizures, skin breakdown, choking, infections, and falls
- Withdraw and sleep more
- Need total help with bathing, dressing, moving and toileting.

Q. Is There A Violent Stage?

A. No. Some people may experience episodes of agitation or aggression, but every person is different. These symptoms are nearly always triggered by something in the environment (e.g., noise, multiple distractions, being rushed by caregivers) or internal distress (e.g., pain, fatigue, boredom). Usually changing the approach or making the person more comfortable alleviates the symptoms. Occasionally, medication is needed as a last resort.

Q. Why Do Symptoms Seem To Come And Go? Is The Resident Just Being Manipulative?

A. The resident with Alzheimer's is not being manipulative. Alzheimer's causes brain damage. The resident has no control over which symptoms he or she will have or when they will occur. People with Alzheimer's have good days and bad days, and it is very common for symptoms to come and go, especially in the early stages.

Q. Can People With AD Live Alone?

A. In the early stages, the disease may be undetectable except to someone who knows the resident well, and even then, perhaps only in retrospect. The resident can usually compensate for any memory deficits by using notes, calendars and other memory aides. Later the resident may still be able to live alone if outside support is provided to help with tasks like bill paying, shopping, and meal preparation.

Eventually, however, the resident will need help with all activities of daily living, including bathing, dressing, and toileting. In the beginning, environmental modifications and intermittent supervision will be sufficient to help the resident cope with their symptoms. For example, signs or pictures can be hung to help the resident locate his or her apartment, or an automatic shut-off can be added to the stove to help protect against fire danger. As the disease progresses the resident will require closer monitoring and increased hands-on care. Eventually, the resident with Alzheimer's will need to move to a more supportive living environment, such as a relative's home or an assisted living or nursing care facility.

Q. When Is It No Longer Safe For A Resident With Alzheimer's To Live Alone?

A. Simply put, when the resident becomes a danger to himself or herself, or to others, and sufficient support services cannot be put in place to correct the problem. Repeated lease violations are often a good indicator of the resident's inability to live self-sufficiently in independent housing. Examples include:

- When the resident is no longer able to maintain the apartment in a safe and sanitary condition
- When the stove is left on and unattended
- When smoking behavior becomes dangerous
- When the resident's behavior is disruptive or threatening to the neighbors.

With assistance from friends, neighbors or agency staff, the resident may still be able to live safely on their own. The bottom line is that the resident must be able to comply with the terms of the lease on his or her own or with assistance.

Q. I Don't Want The Resident To Be Evicted; Shouldn't I Just Leave The Person Alone?

A. Ignoring the situation will only make things worse. The resident may become more confused and unsafe or neighbors may grow frustrated and angry with his or her behavior. Reporting your observations to the property manager or to the Resident Service Coordinator initiates a process that will keep the person safe and give him or her the best chance of remaining in his or her own home. The goal of intervention is to get necessary services in place. Eviction is the last resort after exhausting all options, including involving the family, emergency contacts, community resources and, when appropriate, Adult Protective Services.

In some instances, *beginning the proceedings for eviction* can provide the leverage needed to get service providers and families involved. For example, the resident and/or his family may be in denial that their loved one has dementia until they are confronted with the evidence of repeated lease violations.

Intervention allows the resident to obtain the help he/she needs whether that means bringing services into the home or moving the person to a more appropriate care setting.

Sources

1. *Keepsake: A Program on Memory, Aging and Alzheimer's*, developed in collaboration with The National Council on the Aging and the Alzheimer's Association, sponsored by Eisai Inc. and Pfizer Inc., 1998.
2. Adapted from *Is It Alzheimer's? Warning Signs You Should Know*, Alzheimer's Disease and Related Disorders Association, Inc., 1996.
3. *An Overview of Alzheimer's Disease and Related Dementias*, Alzheimer's Disease and Related Disorders Association, Inc., 1997.
4. *Keepsake: A Program on Memory, Aging and Alzheimer's*, developed in collaboration with The National Council on the Aging and the Alzheimer's Association, sponsored by Eisai Inc. and Pfizer Inc., 1998.
5. Adapted from *Home Is Where I Remember Thing: A Curriculum for Home and Community Alzheimer Care*, by Lisa P. Gwyther, Duke Alzheimer's Family Support Program, Duke University Medical Center, Durham, North Carolina, 1997; and *Care of Alzheimer's Patients: A Manual for Nursing Home Staff*, American Health Care Association and Alzheimer's Disease and Related Disorders Association, 1985.

Resources And Further Reading

1. *Alzheimer's Awareness Training Packet*, developed by Evelyne Tunley-Daymude, Ph.D., Director of Education, Alzheimer's Association Alaska Chapter. For more information, call 1-800-478-1080.
 2. *Alzheimer's Disease: A Handbook for Caregivers*, (Third Edition), by Ronald C. Hamdy, MD, et al., 1998. To order, contact the Maine Alzheimer's Association at 1-800-660-2871, or visit the web site at www.mainealz.org
 3. *Caregiving at a Glance: Fingertip Help for Families Taking Care of People With Alzheimer's Type Illnesses*, (Second Edition), by Lin E. Noyes, Family Respite Center, Falls Church, Virginia, 2000. To order, contact the Maine Alzheimer's Association at 1-800-660-2871, or visit the web site at www.mainealz.org
 4. *"Home Is Where I Remember Things:" A Curriculum for Home and Community Alzheimer Care*, by Lisa P. Gwyther, Duke University Medical Center, Durham, North Carolina, 1997.
 5. *Caring for People With Dementia: A Training Guide*, published by The Training Collaborative, a joint project of the Maine Alzheimer's Association, Alzheimer's Care Center, Gardiner; Muskie School of Public Service at the University of Southern Maine and the Maine Alzheimer's Project, April 1998. For more information, contact the Maine Alzheimer's Association at 1-800-660-2871.
 6. *The 36-Hour Day* (Third Edition), by Nancy L. Mace and Peter V. Rabins, The Johns Hopkins University Press, Baltimore, 1999.
 7. *Care of Alzheimer's Patients: A Manual for Nursing Home Staff*, by Lisa P. Gwyther, ACSW, American Health Care Association and the Alzheimer's Association, 1995. To order, contact the Maine Alzheimer's Association at 1-800-660-2871, or visit the web site at www.mainealz.org
- ➔ You can also order the following brochures by calling the Maine Alzheimer's Association at 1-800-660-2871.
- *Is It Alzheimer's? Warning Signs You Should Know*
 - *Steps to Getting a Diagnosis*
 - *An Overview of Alzheimer's Disease and Related Dementias*

Appendix 2.1

Steps to Getting A Diagnosis

- **Determination of Medical History.** The person being tested and family members will be interviewed both individually and together to gather background information on the person's daily functioning, current medical and physical conditions, and family medical history.
- **Mental Status Evaluation.** During the mental status evaluation, the person's sense of time and place, and ability to remember, understand, talk and do simple calculations will be assessed. The person may be asked questions such as: "What year is it?" "What day of the week is it?" "Who is the current president?" The person will be asked to complete mental exercises, such as spelling a word backwards, writing a sentence, or copying a design. When reviewing the test results, the physician will consider the individual's overall performance in relation to his or her educational background and occupation.
- **Physical Examination.** During the physical exam, the physician will evaluate the person's nutritional status and check blood pressure and pulse. The physician will also search for the presence of cardiac, respiratory, liver, kidney, and thyroid diseases, and atherosclerosis (hardening of the arteries). Some of these conditions can cause dementia-like symptoms.
- **Neurological Exam.** A physician, usually a neurologist, will closely evaluate the person's nervous system for problems that may signal brain disorders other than Alzheimer's disease. The physician will search for evidence of previous strokes, Parkinson's disease, hydrocephalus (fluid accumulation in the brain), a brain tumor, and other illnesses that impair memory and/or thinking. The physician will learn about the health of the brain by testing coordination, muscle tone and strength, eye movement, speech and sensation. For example, the physician will test reflexes by tapping the knee, checking the person's ability to sense feeling on their hands and feet, and listening for slurred speech.
- **Laboratory Tests.** A variety of laboratory tests will be ordered by the physician to help diagnose Alzheimer's disease by ruling out other disorders. A complete blood count and blood chemistry will be ordered to detect anemia, infection, diabetes, and kidney and liver disorders. Levels of vitamin B12 and folic acid (a vitamin produced by the body) are measured, as low levels can be associated with dementia. Since very high or low amounts of the thyroid hormone can cause confusion or dementia, levels of the thyroid hormone are measured through a blood test.

Continued

The physician may also order an EEG (electroencephalogram) to detect abnormal brain wave activity. This test can detect conditions such as epilepsy, which can sometimes cause prolonged mild seizures that leave a person in a confused state.

A CT (computerized tomography) scan, which takes x-ray images of the brain, is sometimes used. The brain is scanned for evidence of tumors, strokes, blood clots and hydrocephalus. MRI (magnetic resonance imaging) is another brain-imaging technique sometimes used. More experimental tests may also be recommended but are not necessary for the diagnosis. These include PET (positron emission tomography), which shows how different areas of the brain respond when the person is asked to perform different activities such as reading, listening to music, or talking; and SPECT (single photon emission computed tomography), which shows how blood is circulating to the brain.

- **Psychiatric, Psychological and Other Evaluations.** A psychiatric evaluation can rule out the presence of other illnesses, such as depression, that can result in memory loss similar to dementia of the Alzheimer type. Neuropsychological testing may also be done to test memory, reasoning, writing, vision-motor coordination, and ability to express ideas. These tests may take several hours, and may involve interviews with a psychologist, as well as written tests. These tests provide more in-depth information than the mental status evaluation.

Nurses, occupational therapists, rehabilitation therapists, or physical therapists may be called upon to look for problems with memory, reasoning, language and judgment affecting the person's daily functioning.

Source: *Steps to Getting a Diagnosis: Finding Out If It's Alzheimer's Disease*, Alzheimer's Disease and Related Disorders Association, 1997.

Appendix 2.2

Alzheimer's Evaluation Programs

**AGES Program (Alzheimer Geriatric Evaluation Services)
University of New England/Southern Maine Medical Center
11 Hills Beach Rd.
Biddeford, ME 04005
(207) 283-4882 or 1-800-930-2437**

Alzheimer's Geriatric Evaluation Services.

James Donahue, DO, Susan Levandoski, RNC, Donna Deletetsky, LSW.

Nurse does intake, screens for appropriateness and schedules appointment.

A two-hour evaluation is done at Southern Maine Medical Center in Biddeford on Thursday afternoons.

Evaluations are also available Wednesday mornings at 50 Holm Avenue (Barron Center campus) in Portland.

Work as interdisciplinary team: nurse does cognitive and functional assessment, social worker interviews family, and physician conducts medical exam. The three-member team then consults and discusses the results of the evaluation with the family. The team communicates with primary care physician and provides recommendations and a written summary.

\$165.00 fee - Medicare or insurance may cover partial fee.

**The Alzheimer's and Memory Center
Neurology Associates of Eastern Maine
498 Essex Street
Bangor, ME 04401
207-947-0558 or 1-800-208-0558**

The Center provides comprehensive services for patients experiencing problems with memory. The team includes neurologists, geriatric psychiatrists, a social worker (LCSW) and a neuropsychologist. Initial evaluation is by a physician and includes a review of the patient history with input from the family, a medical exam and testing for reversible causes of memory loss, a cognitive screening and a functional assessment. Patients may be referred to a neuropsychologist for further cognitive testing. The social worker provides counseling to patients and family members, information and access to community resources, and help with safety concerns. These professionals meet regularly in a multidisciplinary conference to discuss the ongoing care of individual patients with Alzheimer's disease and related disorders.

Detailed reports are sent to the family doctor and/or referring physician. Patients and family members may call for appointments. Most services covered by Medicaid, Medicare or private insurance; however, please call to confirm.

**Community Health and Counseling Services
and Maine Coast Physician's Affiliate**

42 Cedar St.

Bangor, ME 04401

(207) 947-0366

Geriatric Evaluation Program for memory disorders/dementias.

Covers Washington, Hancock, Penobscot and Piscataquis Counties.

Evaluation done by appointment in the individual's home.

Nurse and Social Worker jointly conduct the evaluation - use mini-mental exam, depression screen, neurological screen.

Physician reviews assessment and consults with the team, then communicates with attending physician.

No fee.

The Center for Healthy Aging

277 State Street

Bangor, ME 04402-0404

(207)-973-7094

Outpatient clinic provided collaboratively by Eastern Maine Medical Center and Rosscare.

CHA team consists of geriatrician, nurse practitioner and social worker.

The team completes a comprehensive assessment of physical, cognitive and psychosocial health status. The assessment includes a physical exam and family interviews, when possible.

Consultation with primary care physician is provided.

CHA participates in the Medicare, Medicaid, and most larger commercial insurance programs.

Gardiner Evaluation Unit

Alzheimer Care Center

154 Dresden Ave.

Gardiner, ME 04345

(207) 626-1773 or 1-800-939-3333

Five two-hour evaluation slots available Monday, Wednesday and Friday in Gardiner, Thursday mornings in Waterville area (Fairfield). Karen Gershman, MD and Jane O'Rourke, LSW.

Evaluation performed by physician and social worker in a medical office.

Home visits are sometimes made locally.

Social worker does intake over the telephone and schedules appointment.

Physician and social worker meet with family and patient separately.

Social worker and physician confer and discuss results with the family.

Written report is mailed to attending/family physician and family.

\$145/hour - Medicare or insurance may cover partial fee.

**Maine Medical Center Geriatric Center
100 US Route One, Unit 114
Scarborough, ME 04074
(207) 885-7591**

The MMC Geriatric Center team consists of a geriatrician, clinical nurse specialist, social worker, dietician, physical and occupational therapists, psychiatrist and psychiatric clinical social worker.

The team assesses physical and psychosocial status by means of physical exams and family interviews.

Communicates with the person's primary physician with recommendations and a written summary.

Medicare, Medicaid and private insurance usually cover the cost.

**Memory Clinic
Cary Medical Center
Caribou, ME 04736
(207) 498-3111 ext. 1394**

Memory evaluation service - Gerontologist/Neurologist, and Dottie Sines, LCSW, and Alzheimer's specialist.

Provides detailed clinical evaluation for Alzheimer's disease and related disorders.

Clinic is held by appointment only; each appointment is 1.5 -2 hours.

Patient meets with RN and physician while the caregiver meets with social worker.

The team does a focused history with caregiver input and works up a differential diagnosis, distinguishes the treatable or reversible conditions, and examines behavioral problems and other safety concerns.

A management plan for the patient is developed and any required follow up visits are scheduled.

Family counseling is provided. The team also examines the availability of community support for the patient and caregiver.

Appendix 2.3

Visiting The Doctor: Tips For Getting The Person To Go

In The Early Stages Of Alzheimer's . . .

It can be difficult to get a resident to go to the doctor for a diagnosis or even for a simple check-up. Be patient, but persistent. Agree with their arguments, but also state your position: "I know you feel you don't need to see a doctor, but I would feel better knowing that you have a clean bill of health." In many cases, older adults are familiar with the symptoms of Alzheimer's and are afraid of getting an actual diagnosis. You may try to reassure the resident that there are some treatable conditions that cause similar symptoms (medications, hearing loss, etc.) Try not to take the resident's disagreements personally. The following suggestions may help.

- ✓ **Have a caregiver go as a patient, too.** If a friend, family member, or caregiver goes for a check-up, too, it may make the resident feel more comfortable about going.
- ✓ **Ask the physician to call to schedule an appointment.** Sometimes you can work with the resident's doctor's office to set up an appointment. For example, the doctor's office might be willing to call to encourage the resident to schedule an appointment if he or she has not been in to see the doctor for some time. You may want to make sure that the doctor is experienced in diagnosing and treating dementia.
- ✓ **Get the doctor or pharmacist involved.** Consider telling the resident that an evaluation or trip to the doctor is required to continue a current prescription.
- ✓ **Call ahead and explain your concerns.** Many individuals in the early stages of Alzheimer's behave well in short social situations, making it difficult for a doctor to pick up on problems. Call ahead and give a description of the resident's behavior, or ask a relative or caregiver to do so.

In The Later Stages of Alzheimer's . . .

As the disease progresses, you may face different obstacles in getting the resident to see his or her doctor. Obstinate behavior and acting out may make the trip difficult. The following suggestions may help the trip go more smoothly.

- ✓ **Keep the message simple.** Get the resident ready to go. If they question where they are being taken, play down the visit to the doctor's office. You can tell them they are

Continued

going to the doctor and then out for lunch or ice cream. This may take the emphasis off the doctor visit. Try to be reassuring, as a trip to the doctor's office may be a frightening prospect for the resident.

- ✓ **Arrange for more than one escort.** If possible, arrange for more than one person to escort the resident to the doctor's office – one to drive, and one to provide companionship to the resident during the ride.
- ✓ **Plan well.** Bring distractions such as snacks or pictures to look at. You may want to call ahead to notify the doctor's office that the resident may be apprehensive upon arrival at the office.
- ✓ **Use other physical problems as an excuse.** If the resident has other ailments, remind him or her that the doctor may be able to prescribe something to help alleviate their discomfort.
- ✓ **A prescription may help calm.** If the resident is extremely anxious or acting out, a prescription may help make the trip easier.
- ✓ **See if the doctor will do a visit to the residence.** It may be rare today, but there are still some visiting physicians. If not the doctor, a nurse practitioner or visiting nurse may be able to do an assessment and report to the resident's physician, as long as the situation at hand is not an emergency.

Reversible Dementias

Drugs

E motional (depression)

M etabolic (thyroid, elevated calcium or albumin)

E yes and Ears (sensory isolation – problems seeing or hearing)

Normal Pressure Hydrocephalus

T umors and other space-occupying lesions

I nfections (sinusitis, urinary tract infection . . .)

A nemia (vitamin B12 deficiency)

Appendix 2.5

The Three D's: Delirium, Depression and Dementia

Characteristics	Dementia	Delirium	Depression
Onset	Slow	Rapid	Rapid
Duration	Usually long-term	Hours to days	Generally weeks to months
Prognosis	Usually irreversible	Reversible	Reversible
Orientation	Becomes disoriented over time	Disoriented	Intact
Mood	Labile, unstable	Changes	Stable – sad, negative
Features	<ul style="list-style-type: none"> ▪ Confusion ▪ Vagueness ▪ Suspicion ▪ Poor memory for recent events ▪ Restlessness ▪ Pacing ▪ Agitation 	<ul style="list-style-type: none"> ▪ Decreased ability to maintain attention ▪ Disorganized thinking ▪ May have psychotic symptoms like hallucinations and paranoia ▪ Speech incoherent at times 	<ul style="list-style-type: none"> ▪ Sense of hopelessness ▪ Feels worthless ▪ Memory disturbances ▪ Suicide thoughts ▪ Sleep/appetite changes ▪ Irritability ▪ Loss of interest ▪ Apathy
Cognitive Function	Impaired	Ability fluctuates	Intact, can be slow
Judgment	Poor	Fluctuates	Appropriate except self-regarding evaluation
Attitude toward diagnosis	Denies disability; attempts to cover up errors/disability	Unaware of disability due to reduced level of consciousness	Focuses on disability

Appendix 2.6

Medications That Cause Cognitive Changes In The Elderly

Anticholinergics

- Over-the-counter sleep aids and cold preparations (antihistamines like Benadryl)
- Antiparkinsonian meds (Cogentin, Artane)
- Antipsychotics
- Tricyclic antidepressants
- Atropine
- Scopolamine
- Antispasmodics

Cardiac and Antihypertensives

- Digitalis
- Nitrates
- Procainamide
- Inderal
- Reserpine
- Hydralazine
- Methyldopa
- Guanethidine
- Clonidine

Diuretics

- HCTZ
- Furosemide

CNS Depressants and Anti-Anxiety Meds

- Alcohol
- Diazepam
- Temazepam (Resoril)
- Triazolam (Halcion)
- Ativan

H2 Receptor Antagonists

- Pepcid
- Tagamet

- Zantac

Continued

Hormonal Therapies

- Thyroid meds
- Steroids, Corticosteroids

Hypoglycemics

Lithium

If you think medication changes may be affecting the resident's cognitive ability, look for:

- Acute changes in mental status, particularly attention, speech, and orientation
- Gait disturbances
- Mood lability, especially irritability
- Signs and symptoms of delirium

Appendix 2.7

Alzheimer's Disease and Related Dementias

What is Dementia?

Dementia is a loss of mental function in two or more areas such as language, memory, visual and spatial abilities, or judgment severe enough to interfere with daily life. Dementia itself is not a disease, but a broader set of symptoms that accompanies certain diseases or physical conditions, including Parkinson's disease, Huntington's disease, Creutzfeldt-Jakob disease, Pick's disease, and Lewy body dementia. Other physical conditions may cause or mimic dementia, such as depression, brain tumors, head injuries, nutritional deficiencies, hydrocephalus, infections (AIDS, meningitis, syphilis) drug reactions, and thyroid problems. Individuals experiencing dementia-like symptoms should undergo diagnostic testing as soon as possible. An early and accurate diagnosis helps to identify reversible conditions, gives patients a greater chance of benefiting from existing treatments, and allows them and their future families more time to plan for the future.

What is Alzheimer's Disease?

Alzheimer's disease (AD) is the most common cause of dementia, affecting as many as 4 million Americans. AD is a degenerative disease that attacks the brain, begins gradually, and progresses at a variable rate. AD results in impaired memory, thinking, and behavior and can last from 3 to 20 years from the time of onset of symptoms. Warnings signs of AD are memory loss that affects job/home skills, difficulty performing familiar tasks, problems finding right words, disorientation as to time and place, poor or decreased judgment, difficulty with learning and abstract thinking, placing things in inappropriate places, changes in mood and personality, and marked loss of initiative. In the last stage of AD, patients are unable to take care of themselves. Recent research has shown links between particular genes and Alzheimer's disease, but in about 90% of AD cases, there is no clear genetic link. With the help of standardized diagnostic criteria, physicians can now diagnose AD with an accuracy of 85-90% once symptoms occur. However, a definitive diagnosis of Alzheimer's disease is possible only through the examination of brain tissue at autopsy.

Multi-Infarct Dementia

Multi-infarct dementia (MID), or vascular dementia, is a deterioration of mental capacity caused by multiple strokes (infarcts) in the brain. These events may be described as ministrokes, where small blood vessels in the brain become blocked by blood clots, causing the destruction of brain tissue. The onset of MID may seem relatively sudden, as it may take several strokes for symptoms to appear. These strokes may damage areas of

Continued

the brain responsible for a specific function as well as produce general symptoms of dementia. As a result, MID is sometimes misdiagnosed as Alzheimer's disease. MID is not reversible or curable, but detection of high blood pressure and other vascular risk factors can lead to a specific treatment that may modify MID's progression. MID is usually diagnosed through neurological examination and brain scanning techniques, such as computerized tomography (CT) scan or magnetic resonance imaging (MRI).

Parkinson's Disease

Parkinson's disease (PD) is a progressive disorder of the central nervous system that affects over one million Americans. In PD certain brain cells deteriorate for reasons not yet known. These cells produce a substance called dopamine, which helps control muscle activity. PD is often characterized by tremors, stiffness in limbs and joints, speech difficulties, and difficulty initiating physical movement. Late in the course of the disease, some patients develop dementia and eventually Alzheimer's disease. Conversely, some Alzheimer's patients develop symptoms of Parkinson's disease. Medications such as levodopa, which converts to dopamine inside the brain, and deprenyl, which prevents degeneration of dopamine-containing brain cells, are used to improve diminished or reduced motor symptoms in PD patients but do not correct the mental changes that occur.

Huntington's Disease

Huntington's Disease is an inherited, degenerative brain disease that causes both physical and mental disabilities and usually begins in mid-life. Early symptoms can vary from person to person but include involuntary movement of the limbs or facial muscles, difficulty concentrating, and depression. Other symptoms include personality change, memory disturbance, slurred speech, and impaired judgment. Children born to a person with HD have a 50% chance of inheriting the gene that causes HD. Today a genetic test is available to confirm a diagnosis of HD and to identify carriers of the HD gene. It is recommended that anyone considering genetic testing talk first with family and/or appropriate medical and counseling professionals. There is no treatment to stop the progression of HD, but the movement disturbances and psychiatric symptoms can be treated with medication.

Creutzfeldt-Jakob Disease

Creutzfeldt-Jakob disease (CJD) is a rare, fatal brain disorder that causes rapid, progressive dementia and other neuromuscular disturbances. CJD is caused by a transmissible agent. Research suggests that the agent differs significantly from viruses and other conventional agents. This newly discovered pathogen is called a "prion," short for "proteinaceous infectious particle," because it consists of protein and transforms normal protein molecules into infectious ones. The disease can be inherited, but the majority of cases are not. Early symptoms of CJD include failing memory, changes in behavior, lack of coordination. As the disease advances, usually very rapidly, mental

Continued

deterioration becomes pronounced, involuntary movements (especially muscle jerks) appear, and the patient experiences severe difficulty with sight, muscular energy, and coordination. Like Alzheimer's disease, a definitive diagnosis of CJD can be obtained only through examination of brain tissue.

Pick's Disease

Pick's disease is also a rare brain disorder, characterized by shrinkage of the tissues of the frontal and temporal lobes of the brain and by the presence of abnormal bodies (Pick's bodies) in the nerve cells of the affected areas of the brain. Pick's disease usually begins between the ages of 40 and 60. The symptoms are similar to Alzheimer's disease, with a loss of language abilities, skilled movement, and the ability to recognize objects or people. Initial diagnosis is based on family history (Pick's disease may be inherited), symptoms, tests, and ruling out other causes of dementia. A definitive diagnosis of Pick's disease is usually obtained at autopsy.

Lewy Body Dementia

Lewy body dementia (LBD) is an irreversible form of dementia associated with abnormal protein deposits in the brain called Lewy bodies. Symptoms of LBD are similar to Alzheimer symptoms and include memory loss, confusion, and difficulty communicating. Hallucinations and paranoia also may become apparent in the earlier stages of the disease and often last throughout the disease process. Although initial symptoms of LBD may be mild, affected individuals eventually develop severe cognitive impairment. At this time, there is no treatment available for Lewy body dementia.

Reprinted from: *Alzheimer's Disease and Related Dementias Fact Sheet*, Alzheimer's Disease and Related Disorders Association, Inc., 1999.

Appendix 2.8

Alzheimer's Disease: Facts and Statistics

Facts

Definition

Alzheimer's disease is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. Alzheimer's disease is the most common form of dementia. Dementia is a loss of intellectual function (thinking, remembering and reasoning) so severe that it interferes with an individual's daily functioning and eventually results in death. Men and women are affected almost equally. The disease was first described by Dr. Alois Alzheimer in 1906. Since then, researchers have developed a deeper understanding of the changes in the brain (plaques and tangles) and behavioral changes that characterize the disease. Identified risk factors are age and family history. Most people diagnosed with Alzheimer's are older than age 65; however, Alzheimer's disease can occur in people in their 30s, 40s and 50s.

Symptoms

Symptoms of Alzheimer's can include gradual memory loss, decline in the ability to perform routine tasks, disorientation, difficulty in learning, loss of language skills, impairment of judgment and planning and personality changes. The rate of progression varies from person to person. The time from the onset of symptoms until death ranges from 3 to 20 years; the average is 8 years. Eventually persons with Alzheimer's disease become totally incapable of caring for themselves.

Diagnosis

Early and careful evaluation is important because many conditions, including some that are treatable or reversible, can cause dementia. Potentially reversible conditions include depression, adverse drug reactions, metabolic changes and nutritional deficiencies.

There is no single clinical test to identify Alzheimer's. A comprehensive evaluation to establish a diagnosis will include a complete health history, physical examination, neurological and mental status assessments and other tests, including analysis of blood and urine, electrocardiogram (EKG) and chest x-rays. Documenting symptoms and behavior over time, in a diary fashion, will help physicians understand the person's illness. The physician may order additional tests as needed, including: computerized tomography (CT scan), electroencephalograph (EEG), formal psychiatric assessment and/or neuropsychological testing. While this evaluation may provide a diagnosis of possible or probable Alzheimer's disease, confirmation of Alzheimer's disease requires examination of brain tissue at autopsy.

Treatment

Although no cure for Alzheimer's disease is currently available, good planning and medical and social management can ease the burdens on the patient and family. Health care directives and decisions can be made while the patient has the mental capacity to do so. Physical exercise and social activity are important, as is proper nutrition. A calm and well-structured environment may help the afflicted person to continue functioning. Intervention strategies and, if necessary, appropriate medication can lessen symptoms such as agitation and anxiety, and improve sleep and participation in activities. Four FDA-approved drugs — tacrine (Cognex®), donepezil (Aricept®), rivastigmine (Exelon®) and galantamine (Reminyl®) — may temporarily relieve some symptoms of the disease.

Causes and research

The causes of Alzheimer's disease are not known and are currently receiving intensive scientific investigation. Suspected causes include diseased genes or a genetic predisposition, abnormal protein build-up in the brain and environmental toxins. Scientists are applying the newest knowledge and research techniques in molecular genetics, pathology, immunology, toxicology, neurology, psychiatry, pharmacology, biochemistry and epidemiology to find the cause, treatments and cure for Alzheimer's disease.

Economic impact

At some point, persons with Alzheimer's disease will require 24-hour care, including assistance with daily activities such as eating, grooming and toileting. The financing of care for Alzheimer's disease — including costs of diagnosis, treatment, nursing home care and formal or paid care — is estimated to be more than \$100 billion each year. It's estimated that Alzheimer's disease costs American businesses more than \$33 billion a year due to the absenteeism of caregivers — employees who take care of people with the disease — and the cost of care.

The Alzheimer's Association is the largest national voluntary health organization dedicated to research for the causes, treatments, prevention and cure of Alzheimer's disease and to providing education and support services to people with the disease, their families and caregivers. A nationwide 24-hour information and referral line links families who need assistance with nearby local chapters. For information or help, call 1-800-272-3900 or contact your local chapter.

Statistics

Prevalence

- Four million people in the United States have Alzheimer's disease. Nineteen million say they have a family member with the disease.

Continued

- By 2050, 14 million people in the United States will have Alzheimer's, unless science finds a way to prevent or cure the disease.
- One in ten persons over the age of 65 — and nearly half of those over 85 — have Alzheimer's. Younger people also get the disease.
- The disease process may begin in the brain as much as 20 years before the symptoms of Alzheimer's appear. A person will live an average of eight years — and as many as 20 years — once the symptoms appear.

Costs

- The average lifetime cost of Alzheimer's disease, per person, is \$174,000.
- The total annual cost of Alzheimer's care in the United States today is at least \$100 billion.
- Alzheimer's disease costs American businesses \$33 billion annually, 79% of which is due to the lost productivity of employees who are caregivers.
- Medicare spent an average of \$7,682 in 1995 on beneficiaries with Alzheimer's disease. That is 70% more than the average of \$4,524 spent on beneficiaries with cognitive impairment.
- Nearly half (49%) of Medicare beneficiaries with Alzheimer's also receive Medicaid. Of those "dually eligible" for Medicare and Medicaid, 22% have Alzheimer's disease.
- Seven in ten people with Alzheimer's disease live at home. While almost 75% of home care is provided by family and friends, the average annual cost of paid care for people with Alzheimer's disease at home is \$12,500.
- At least half of all nursing home residents have Alzheimer's disease or another dementia. The average annual cost of Alzheimer nursing home care is \$42,000 but exceeds \$70,000 in some areas. Medicaid pays more than half of the total nursing home bill and helps 2 out of 3 residents pay for their care.
- In fiscal year 2001, the federal government will spend an estimated \$515 million on Alzheimer's research — a modest investment when compared to the annual \$100 billion cost of the disease. If science can find a way to delay the onset of Alzheimer's even for five years, it will save at least \$50 billion in annual health and long-term care costs.

Source: Alzheimer's Disease and Related Disorders Association, Inc., 2000.

Appendix 2.9

Is It Alzheimers? Ten Early Warning Signs

Alzheimer's disease is not just memory loss. People with Alzheimer's disease experience a decline in cognitive abilities, such as thinking and understanding, and changes in behavior. To help you determine if you have any of these symptoms, the Alzheimer's Association has developed a list of warning signs that include common symptoms of Alzheimer's disease (some also apply to other dementias). If someone you know has several of these symptoms, he or she should see a physician for a complete examination.

- 1. Memory loss that affects job skills.** It's normal to occasionally forget an assignment, deadline, or colleague's name, but frequent forgetfulness or unexplainable confusion at home or in the workplace may signal that something's wrong.
- 2. Difficulty performing familiar tasks.** Busy people get distracted from time to time. For example, you might leave something on the stove too long or not remember to serve part of a meal. People with Alzheimer's might prepare a meal and not only forget to serve it but also forget they made it.
- 3. Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute inappropriate words, making his or her sentences difficult to understand.
- 4. Disorientation to time and place.** It's normal to momentarily forget the day of the week or what you need from the store. But people with Alzheimer's disease can become lost on their own street, not knowing where they are, how they got there, or how to get back home.
- 5. Poor or decreased judgment.** Choosing not to bring a sweater or coat along on a chilly night is a common mistake. A person with Alzheimer's, however, may dress inappropriately in more noticeable ways, wearing a bathrobe to the store or several blouses on a hot day.
- 6. Problems with abstract thinking.** Balancing a checkbook can be challenging for many people, but for someone with Alzheimer's, recognizing numbers or performing basic calculation may be impossible.
- 7. Misplacing things.** Everyone temporarily misplaces a wallet or keys from time to time. A person with Alzheimer's disease may put these and other items in inappropriate

places — such as an iron in the freezer or a wristwatch in the sugar bowl — and then not recall how they got there.

Continued

8. Changes in mood or behavior. Everyone experiences a broad range of emotions — it's part of being human. People with Alzheimer's tend to exhibit more rapid mood swings for no apparent reason.

9. Changes in personality. People's personalities may change somewhat as they age. But a person with Alzheimer's can change dramatically, either suddenly or over a period of time. Someone who is generally easygoing may become angry, suspicious, or fearful.

10. Loss of initiative. It's normal to tire of housework, business activities, or social obligations, but most people retain or eventually regain their interest. The person with Alzheimer's disease may remain uninterested and uninvolved in many or all of his usual pursuits.

Source: Alzheimer's Disease and Related Disorders Association, Inc. Updated 3/00.

Appendix 2.10

Stages and Symptoms

<p>Stage One: Two-to- four years in duration. During this stage, the individual with Alzheimer’s may still be working or living alone.</p>	<p>Symptoms Include:</p> <ul style="list-style-type: none"> ▪ Anxious about symptoms ▪ Forgetful — loss of short-term memory ▪ Problems at work involving poor judgment ▪ Decline in grooming ▪ Repeats a lot, trouble finding right words ▪ Trouble managing money ▪ Mild disorientation ▪ Mood swings ▪ Easily angered, frustrated ▪ Slower to learn and slower to react ▪ Loses zest for life
<p>Stage Two: Two-to- ten years in duration, marked by increased memory loss and confusion. The person with Alzheimer’s may still be functioning in some ways, but needs more help.</p>	<p>Symptoms Include:</p> <ul style="list-style-type: none"> ▪ Repeats more ▪ Lives in the past ▪ Slower gait, some shuffling ▪ Unable to recognize people ▪ Difficulty communicating, finding words ▪ Difficulty reading ▪ Increased fears, paranoia ▪ Bowel and bladder problems ▪ Sleep disturbances ▪ Increased motor problems, difficulty using objects ▪ Needs assistance with Activities of Daily Living (ADLs) ▪ Restlessness in afternoon/evening ▪ Agitation ▪ Possible hallucinations or delusions ▪ Forgets when last meal was eaten, may lose interest in food
<p>Stage Three: During this time, the person with Alzheimer’s will be almost entirely dependent on others for</p>	<p>Symptoms Include:</p> <ul style="list-style-type: none"> ▪ Unable to carry on any meaningful conversation ▪ Incontinent, dependent on caregiver for all personal needs ▪ Mis-identifies people and objects ▪ May have increased or decreased appetite, gains or loses weight, eventually loses weight

daily needs and care.	<ul style="list-style-type: none"> ▪ Falls frequently ▪ Difficulty swallowing ▪ May have seizures ▪ Sleeps more ▪ Increased frailty ▪ Probably becomes bedridden
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Appendix 2.11

Facts About Cognex and Alzheimer's Disease

What is tacrine?

Tacrine (Congex[®]) was approved in 1993 by the U.S. Food and Drug Administration (FDA) specifically to treat Alzheimer's disease. It is not a cure for Alzheimer's disease, nor does it appear to stop the progression of the disease.

How does tacrine work?

In Alzheimer's disease, nerve cells in regions of the brain responsible for memory and other thought processes degenerate and die for unknown reasons. Some of the most severely affected cells communicate by means of the neurotransmitter acetylcholine, which becomes deficient as the disease progresses. Normally, acetylcholine is produced by these nerve cells, released to carry messages to other nerves, and then broken down. Tacrine inhibits the action of cholinesterase, one of the enzymes that breaks down acetylcholine. This inhibition increases the amount of acetylcholine available for cell-to-cell communication, which may relieve some of the memory impairment and other symptoms associated with Alzheimer's.

Is tacrine effective in all Alzheimer patients?

From what is currently known, tacrine will improve the condition of only a minority of Alzheimer patients. To date, tacrine has only been studied in people with mild to moderate Alzheimer's who were otherwise in generally good health (without heart, lung, liver, or kidney disease). It is currently approved for use only in mild to moderate stages. There is no way to predict whether or not tacrine will help an individual Alzheimer patient.

What are the side effects of tacrine?

The most common side effect of tacrine is an increase in a particular liver enzyme (alanine aminotransferase, or ALT). An increase in ALT can signal liver damage. When a person starts taking tacrine, blood will be drawn on a regular basis to measure ALT. Through regular monitoring, the doctor will learn whether the patient shows an increase in ALT, and if so, adjust the dosage of tacrine accordingly. Other frequent side effects include nausea, vomiting, diarrhea, abdominal pain, indigestion, and skin rash. Any time a person begins taking a new drug, the doctor, patient, and family member(s) should discuss what potential side effects the drug may have, and how the drug may interact with other drugs being taken (prescription or over-the-counter).

How can a patient get tacrine?

Tacrine is available only by prescription from your doctor. Because there is no known way to predict whether any individual Alzheimer patient will experience a beneficial

Continued

response or side effects, it is important to have a thorough discussion with your doctor about the possible results of treatment with tacrine. Through this discussion, you and your doctor can weigh tacrine's possible benefits, risks, and costs in order to decide whether or not to try it.

What questions should you ask the doctor?

- What are the potential benefits of taking the drug?
- How long should the person take the drug before a response can be detected?
- What dosage do you recommend?
- What if I miss taking a dose?
- What are the known side effects?
- Should the person taking tacrine stop taking the drug immediately if side effects occur?
- What changes in the patient's condition should be reported immediately?
- What happens if the drug is stopped suddenly?
- What drugs (prescription and over-the-counter) might interact with tacrine?
- How might this drug affect other conditions?
- How often will the patient have to visit the clinic?
- Can an Alzheimer's resident in a continuing care facility take this medication?
- What are the costs associated with tacrine?

Are there other drugs available to treat symptoms of Alzheimer's disease?

There are other FDA-approved drugs currently available for treatment of Alzheimer's: Donepezil hydrochloride (Aricept[®]), rivastigmine (Exelon[®]), and galantamine (Reminyl[®]). These drugs work in a manner similar to tacrine – by increasing the brain's supply of acetylcholine. There are also several experimental Alzheimer's drugs under investigation at study sites nationwide. To obtain fact sheets that provide further details about these studies, please contact the Maine Alzheimer's Association at 1-800-660-2871 or visit the web site at www.mainealz.org

What other measures can improve the experience of Alzheimer's disease for affected individuals and their families?

Through their collective experience, family and professional caregivers have developed a wide range of strategies to help manage symptoms of Alzheimer's disease, and to help reduce the impact of this disease has on everyone affected. Such strategies include environmental and behavioral modifications, activity programs, and support and respite services. For information about resources in Maine, contact the Maine Alzheimer's Association at 1-800-660-2871 or visit the web site at www.mainealz.org

Source: Alzheimer's Disease and Related Disorders Association, Inc. This fact sheet is provided for your information only, and does not represent an endorsement of tacrine by the Alzheimer's Association.

Appendix 2.12

Facts About Donepezil Hydrochloride (Aricept)

Donepezil hydrochloride (also known as Aricept® and by the investigational designation E2020) was the second drug approved by the U.S. Food and Drug Administration (FDA) specifically to treat symptoms of Alzheimer's disease. It is not a cure for Alzheimer's, nor does it appear to stop progression of the disease.

How does donepezil work?

In Alzheimer's disease, nerve cells in regions of the brain responsible for memory and other thought processes degenerate and die for unknown reasons. Some of the most severely affected cells communicate by means of the neurotransmitter acetylcholine, which becomes deficient as the disease progresses. Normally, acetylcholine is produced by these nerve cells, released to carry messages to other nerves, and then broken down. Donepezil inhibits the action of cholinesterase, one of the enzymes that breaks down acetylcholine. This inhibition increases the amount of acetylcholine available for cell-to-cell communication, which may relieve some of the memory impairment and other symptoms associated with Alzheimer's.

Is donepezil effective in all individuals with Alzheimer's?

Donepezil is approved for treatment of mild to moderate Alzheimer's. Because the number of functioning nerve cells declines as the disease progresses, this drug may not be as effective for individuals in advanced stages of the disease. No differences in the effectiveness of donepezil were observed based on age, sex, or race of the individuals who were treated during clinical trials.

What is the usual daily dosage?

Donepezil is administered once daily at bedtime, and can be taken with or without food. It is available in 5mg or 10mg tablets, and the dosage should be prescribed by a physician.

What are the side effects?

The most frequent side effects of donepezil include diarrhea, nausea and vomiting, insomnia, fatigue, and loss of appetite. In most cases, these side effects were observed to be mild, usually lasting from one to three weeks and declining with continued use of the

drug. Whenever a person begins taking a new drug, the doctor, patient, and family member(s) should discuss what the potential side effects may be, and how the drug may interact with other prescription or over-the-counter drugs that are being taken.

Continued

How and where can you get donepezil?

Donepezil is available only prescription from a doctor. Because there is no known way to predict whether or not an individual with Alzheimer's disease will benefit from the use of donepezil, it is important to have a thorough discussion with the doctor about the possible results of treatment with this drug. Through this discussion, you and your doctor can weigh the possible benefits, risks, and costs associated with donepezil.

What questions should you ask the doctor?

- What are the potential benefits of taking the drug?
- How long should a person take the drug before a response can be detected?
- What dosage do you recommend for me?
- What should I do if I miss taking a dose?
- What are the known side effects?
- Should the person taking donepezil stop taking the drug immediately if side effects occur?
- What changes in the patient's condition should be reported immediately?
- What happens if the drug is stopped suddenly?
- What drugs (prescription and over-the-counter) might interact with donepezil?
- How might this drug affect other conditions?
- How often will the patient have to visit the clinic?
- Can an Alzheimer's resident in a continuing care facility take this medication?
- What are the costs associated with donepezil?

Are there other drugs available?

There are three other FDA-approved drugs currently available for treatment of Alzheimer's: tacrine (Cognex[®]), Rivastigmine (Exelon[®]), and galantamine (Reminyl[®]). These drugs work in a manner similar to donepezil – by increasing the brain's supply of acetylcholine. There are also several experimental Alzheimer's drugs under investigation at study sites nationwide. To obtain fact sheets about investigational drugs or open clinical trials, please call the Maine Alzheimer's Association toll-free at 1-800-660-2871.

What other measures can improve the experience of Alzheimer's disease for affected individuals and their families?

Through their collective experience, family and professional caregivers have developed a wide range of strategies to help manage symptoms of Alzheimer's disease, and to help reduce the impact of this disease has on everyone affected. Such strategies include environmental and behavioral modifications, activity programs, and support and respite services. For information about resources in Maine, contact the Maine Alzheimer's Association at 1-800-660-2871 or visit the web site at www.mainealz.org

Source: Alzheimer's Disease and Related Disorders Association, Inc. This fact sheet is provided for your information only, and does not represent an endorsement of donepezil by the Alzheimer's Association.

Appendix 2.13

Facts About Rivastigmine (Exelon®)

Rivastigmine tartrate (also known by the trade name Exelon® and the investigational designation ENA-713) is the third drug approved by the U.S. Food and Drug Administration (FDA) specifically to treat the symptoms of Alzheimer's disease. It is also approved as an Alzheimer treatment in many other countries around the world. In clinical trials, participants taking rivastigmine showed greater improvement than those receiving a placebo (inactive treatment) in cognitive abilities such as thinking and remembering, in activities of daily living such as dressing and self-care, and in overall functioning. However, rivastigmine did not help everyone who took it. It is not a cure for Alzheimer's and does not stop progression of the fundamental disease process.

How does rivastigmine work?

In Alzheimer's disease, nerve cells in regions of the brain responsible for memory and other thought processes degenerate and die for unknown reasons. Some of the most severely affected cells communicate by means of the neurotransmitter acetylcholine, which becomes deficient as the disease progresses. Normally, acetylcholine is produced by these nerve cells, released to carry messages to other nerves, and then broken down. By damaging and killing nerves in the acetylcholine system, Alzheimer's disease disrupts the brain's communication network and decreases the amount of acetylcholine available to carry messages among surviving nerves.

Is it effective in all individuals?

Rivastigmine is approved for treatment of mild to moderate Alzheimer's disease. In clinical trials enrolling people with mild to moderate stages of Alzheimer's, rivastigmine helped slightly more than 50 percent of participants who received the drug. There is no known way to predict who may benefit from taking it. Studies did not reveal any differences in the drug's effectiveness based on age, sex, or race. More than 90 percent of trial participants had – in addition to Alzheimer's disease – a variety of other illnesses common in older adults, including hypertension, Type 2 (adult onset) diabetes, and arthritis. Almost all enrollees took other medications at the same time that they took rivastigmine.

Because the number of functioning nerve cells declines as Alzheimer's progresses, rivastigmine may offer less symptom relief for individuals in advanced stages of the

disease. Additional clinical trials are in progress to assess the drug's effectiveness in treating individuals with moderately severe to severe Alzheimer's. An additional study – "Investigation into Delay to Diagnosis of Alzheimer's Disease with Exelon®" (InDDEx) – explores rivastigmine's ability to delay or prevent progression from mild cognitive impairment to Alzheimer's. You can request a copy of the Alzheimer's Association information fact sheet "Facts about the InDDEx Study" by calling them toll-free at 1-800-272-3900 or by visiting their web site at www.als.org

Continued

How is Exelon® supplied?

Rivastigmine is supplied in the form of capsules in strengths of 1.5, 3.0, 4.5, and 6.0 milligrams. Consult your physician for dosing information.

What are the side effects?

The most common side effects include indigestion, nausea and vomiting, loss of appetite, weakness, fatigue, and weight loss. In most cases, these effects are temporary and tolerable, declining with continued use of the drug. Individuals with Alzheimer's who are considering a new medication should meet with their doctor and family members to discuss potential side effects and understand how the new treatment may interact with other prescription or over-the-counter drugs they are taking.

How and where can you get rivastigmine?

The FDA approved it in April 2000. A doctor must prescribe rivastigmine. Novartis Pharmaceuticals, its developer, has established a toll-free line for people who would like more information about rivastigmine at 877-439-3566.

What questions should you ask the doctor?

- What are the potential benefits of taking the drug?
- How long should a person take the drug before a response can be detected?
- What dosage do you recommend for me?
- What should I do if I miss taking a dose?
- What are the known side effects?
- Should the person taking rivastigmine stop taking the drug immediately if side effects occur?
- What changes in the patient's condition should be reported immediately?
- What happens if the drug is stopped suddenly?
- What drugs (prescription and over-the-counter) might interact with rivastigmine?
- How might this drug affect other conditions?
- How often will the patient have to visit the clinic?
- Can an Alzheimer's resident in a continuing care facility take this medication?
- What are the costs associated with rivastigmine?

Are other drugs available to treat Alzheimer's?

The FDA currently approves three other drugs for treatment Alzheimer's symptoms: donepezil hydrochloride (Aricept®), tacrine (Cognex®), and galantamine (Reminyl®). These drugs work in a manner similar to rivastigmine's – they inhibit an enzyme that breaks down acetylcholine. There are also several experimental Alzheimer's drugs under

investigation at study sites nationwide. To obtain fact sheets about investigational drugs or open clinical trials, please call the Maine Alzheimer's Association toll-free at 1-800-660-2871 or visit the web site at www.mainealz.org

Continued

What other measures can improve the experience of Alzheimer's disease for affected individuals and their families?

Through their collective experience, family and professional caregivers have developed a wide range of strategies to help manage symptoms of Alzheimer's disease, and to help reduce the impact of this disease has on everyone affected. Such strategies include environmental and behavioral modifications, activity programs, and support and respite services. For information about resources in Maine, contact the Maine Alzheimer's Association at 1-800-660-2871 or visit the web site at www.mainealz.org

Source: Alzheimer's Disease and Related Disorders Association, Inc. This fact sheet is provided for your information only, and does not represent an endorsement of rivastigmine by the Alzheimer's Association.

Appendix 2.14

Facts About Galantamine Hydrobromide (Reminyl®)

Galantamine Hydrobromide (also known by the trade name Reminyl® and the investigational designation R113675) is the fourth prescription drug approved by the U.S. Food and Drug Administration (FDA) specifically to treat symptoms of Alzheimer's disease. It is also approved as an Alzheimer treatment in the European Union and several other countries around the world.

In clinical trials comparing galantamine to placebo (inactive treatment), participants taking galantamine experienced better results than participants in the placebo group in measures of thinking and reasoning, day-to-day functioning, and behavior. Although galantamine recipients performed better as a group, the drug did not help every individual who took it. It is not a cure for Alzheimer's, and does not appear to stop disease progression.

How does galantamine work?

In Alzheimer's disease, nerve cells in brain regions important for memory, thought, and judgment degenerate and die for unknown reasons. Some of the most severely affected nerves communicate by means of the neurotransmitter acetylcholine. Normally, acetylcholine is produced by these cells, released to carry signals to other nerves, then broken down for reuse. By damaging and killing nerves in the acetylcholine system, Alzheimer's disease disrupts the brain's communication network and decreases the amount of acetylcholine available to carry messages among surviving nerves.

Galantamine inhibits the action of cholinesterase, one of the enzymes that breaks down acetylcholine. This inhibition increases the amount of the chemical available for cell-to-cell communication, which may relieve some of the memory impairment and other symptoms associated with Alzheimer's. In addition, galantamine appears to stimulate release of acetylcholine and to strengthen the way that certain receptors on message-receiving nerve cells respond to it.

Is it effective in all individuals with Alzheimer's?

Like the three previously approved Alzheimer drugs – tacrine, donepezil, and rivastigmine – galantamine is approved for treatment of mild to moderate Alzheimer's disease. All of these drugs are designed primarily to inhibit breakdown of acetylcholine. There is no known way to predict who may benefit more from taking one drug rather than one of the others; however, patients who do not benefit from one may respond favorably to another.

Where can I get it and how is it supplied?

Galantamine is available only with a physician's prescription. Janssen Pharmaceutica, the manufacturer, anticipated that the drug would be available in pharmacies by May 2001. It is supplied in the form of tablets in strengths of 4, 8, and 12 milligrams.

What are the side effects?

The most frequent side effects of galantamine include nausea, diarrhea, and other gastrointestinal symptoms. They are usually mild and temporary, improving with ongoing treatment. People with Alzheimer's who are considering taking a new medication should meet with their doctor's and family members to discuss potential side effects and how the new treatment may interact with other prescription or over-the-counter drugs they are taking.

What questions should you ask the doctor?

- What are the potential benefits of taking the drug?
- How long should a person take the drug before a response can be detected?
- What dosage do you recommend for me?
- What should I do if I miss taking a dose?
- What are the known side effects?
- Should the person taking galantamine stop taking the drug immediately if side effects occur?
- What changes in the patient's condition should be reported immediately?
- What happens if the drug is stopped suddenly?
- What drugs (prescription and over-the-counter) might interact with galantamine?
- How might this drug affect other conditions?
- How often will the patient have to visit the clinic?
- Can an Alzheimer's resident in a continuing care facility take this medication?
- What are the costs associated with galantamine?

Are there other drugs available to treat symptoms of Alzheimer's?

The FDA currently approves three other drugs specifically to treat symptoms of Alzheimer's disease – tacrine (Cognex®) donepezil hydrochloride (Aricept®) and rivastigmine (Exelon®). All of these drugs have primary mechanisms of action similar to galantamine's – they inhibit breakdown of acetylcholine. There are also several experimental Alzheimer's drugs under investigation at study sites nationwide. To obtain fact sheets about tacrine, donepezil, or rivastigmine, investigational drugs, or to learn more about open clinical trials, please call the Maine Alzheimer's Association toll-free at 1-800-660-2871 or visit our web site at www.mainealz.org

Source: Alzheimer's Disease and Related Disorders Association, Inc. This fact sheet is provided for your information only, and does not represent an endorsement of galantamine by the Alzheimer's Association.

Chapter 3

Guidelines for Communication

“It’s not what you say, it’s how you say it. . . .”

Mom

Communication is the process of sending and receiving messages that allows us to relate to one another. Through communication we convey our thoughts and feelings, wishes and ideas. It helps us express who we are. Communication is more than talking and listening with words. It involves attitude, tone of voice, facial expressions, and body language. A resident with Alzheimer’s disease experiences problems expressing himself or herself with words and understanding what others are saying.

Changes In Communication

Although there will be variations from individual to individual among people with Alzheimer’s, language is usually affected early in the disease, and communication becomes harder as time goes by. Common language changes include:¹

- Not recognizing a word or a phrase, almost as if the word were in a foreign language
- Not being able to name things (noun finding)
- Substituting a word that sounds like the word they want or using a general instead of a specific word (such as saying “that girl” instead of “Jane” or “my daughter”)
- Getting stuck on ideas or words, repeating them over and over
- Easily losing a train of thought
- Forgetting how to carry on a polite conversation; they may curse, talk silly or say tactless things to people
- Losing the ability to comprehend what they have just read; gradual worsening of writing ability
- Returning to their native language, or more commonly, combining languages with little insight into which language they are speaking at the time
- Speaking less often, or using only a few words or nonsense syllables
- Relying on nonverbal gestures more

Actions Speak Louder Than Words

As verbal communication becomes increasingly difficult for a resident with Alzheimer's disease, he or she usually retains the ability to understand and use nonverbal communication. Be aware that the resident will be very sensitive to your mood, facial expression, tone of voice and body language. These nonverbal messages will convey your "true" message more so than the actual words that you use.

Pay special attention to your body language: ²

- Always approach the resident from the front and avoid sudden movements.
- Use eye contact to get and keep the resident's attention.
- Be aware of your stance to avoid sending a negative message.
- Use positive and friendly facial expressions.
- Use nonverbal gestures such as pointing, gesturing and touching.

Be aware of the tone you use: ³

- Speak slowly and distinctly.
- Use a gentle and relaxed tone of voice. A lower pitch is more calming.
- Convey an easygoing, non-demanding manner of speaking.
- Be aware of your feelings and attitude. They're often communicated, unintentionally, through tone of voice.

The reverse is also true. The resident's behavior will gradually become his or her primary mode of communication. Ask: What is the resident's behavior *saying* that he or she can no longer express in words?

Helping The Resident With Alzheimer's Communicate: Your Approach To Listening ⁴

- **Be patient and supportive.** Let the resident know that you are listening and trying to understand what he/she is saying. Never show through words, gestures or facial expressions that you are impatient to move things along. "It's okay, Bill, take your time."
- **Show your interest.** Smile, maintain eye contact, lean forward and show that you care about what the resident is saying. "I really want to hear what you have to say."
- **Offer comfort and reassurance.** If the resident is having difficulty expressing themselves, let them know that it is all right. Encourage him or her to continue.
- **Listen for a response.** It may take up to thirty seconds for the resident to figure out what you have said and come up with the right words in response. Be careful not to interrupt.

- **Avoid criticizing or correcting.** Don't tell the resident that what they are saying is incorrect. Instead, listen and try to find the meaning in what is being said. Repeat what was said if clarification is needed.
- **Don't argue.** If the resident says something you don't agree with, let it be. It's impossible to have a rational argument with someone who has lost the capacity to be rational. Arguing often only makes things worse. Respond to the feelings being expressed, then distract by changing the subject, asking for the resident's help, or offering an alternative activity.
- **Offer a guess.** If the resident uses the wrong word or cannot find a word, try helping them out ("Is it a spoon you're thinking about, Jane?"). If you understand what he or she means, it may not be necessary to provide the correct word. In either case, be careful not to cause unnecessary frustration by correcting the resident or acting impatient.
- **Focus on feelings, not facts.** Sometimes, the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may help you to understand how the resident is really feeling. Help the resident to name his or her feelings: "You look sad."
- **Limit distractions.** Find a place that is quiet, so that you won't be interrupted and the resident can focus on he or she wants to say.
- **Encourage non-verbal communication.** If you don't understand what he or she is trying to say, ask them to point or gesture.

Always speak to an older resident as though they can understand every word you are saying . . . because their ability to understand you often outlasts their ability to speak appropriately.

Be respectful and kind — *always!*

Your Approach To Communicating⁵

When communicating with a resident with Alzheimer's, words must be chosen carefully. The following techniques will make it easier for the resident to understand you.

Get the resident's attention before speaking

- Approach from the front, slowly.

- Get on the same level or height as the resident to whom you are speaking.
- Maintain eye contact (without staring).
- Use gentle touch, as appropriate.
- ➔ **TIP:** Address the resident by name. This is not only courteous, but also helps orient the resident and get his or her attention.

Set a good tone

- Use a calm, gentle matter-of-fact manner.
- Smile, and speak with a low-pitched, reassuring tone of voice.
- Introduce yourself, no matter how obvious it seems.
- Start with social conversation to help the resident relax, and to gain his or her trust before moving on to the task.
- ➔ **TIP:** If you leave the room, or are interrupted, start over.

Slow down

- Expect things to take longer; the resident is doing the best they can with an impaired memory.
- Don't act rushed or impatient, and ask one question at a time.
- Give the resident time and encouragement to process and respond to your request.
- ➔ **TIP:** If you need to repeat information, do so using the same words and phrases as before.

Simplify

- Speak clearly and distinctly.
- Use short, familiar words and avoid long explanations or requests.
- In a group situation, allow only one resident to talk at a time.
- Turn questions into answers. For example, say "The bathroom is right here" instead of asking "Do you need to use the bathroom?"
- Emphasize key words, such as, "Here is your *coffee*."
- ➔ **TIP:** Communicate one idea or task at a time, and break tasks and instructions into clear, simple steps, giving one step at a time.

Use nonverbal cues

- Demonstrate your requests by pointing, touching or beginning the task for a resident.
- Use written explanations for reminders or when verbal ones seem too confusing.
- ➔ **TIP:** If you don't understand what the resident is saying, encourage them to point or to gesture.

Pitfalls to avoid

- Avoid literal expressions such as "Hop in!" which may be taken literally and cause unnecessary confusion.
- Avoid pronouns. Instead of saying "Here it is," try "Here is your hat."

- Make negatives more positives. Instead of saying, “Don’t go there,” try saying, “Let’s go here.”
 - Avoid quizzing. Some reminiscence can be healthy, but avoid asking “Do you remember when...?” or using statements like, “You should know who that is.”
 - Avoid arguing.
 - Avoid talking down to the resident with dementia and don’t speak about the resident as though he or she isn’t there.
- ➔ **TIP:** Always speak to each resident as if they understand every word you are saying, because the ability to understand often outlasts the ability to speak appropriately. Always be respectful and kind.

Tips for Better Communication

- Be calm and supportive.
- Focus on feelings, not facts.
- Pay attention to tone of voice.
- Identify yourself and address the resident by name.
- Speak slowly and clearly.
- Use short, simple and familiar words.
- Ask one question at a time.
- Allow enough time for a response.
- Avoid the use of pronouns, negative statements and quizzing.
- Use nonverbal communication such as pointing and touching.
- Offer assistance as needed.
- Don’t talk about the resident as if he wasn’t there.
- Have patience, flexibility and understanding.

Source: *Steps to Enhancing Communication*, Alzheimer’s Disease and Related Disorders Association, Inc. 1997.

Sources

1. Adapted from “*Home Is Where I Remember Things*,” *A Curriculum for Home and Community Alzheimer Care*, by Lisa P. Gwyther, Duke Alzheimer’s Family Support Program, Duke University Medical Center, Durham, North Carolina, 1997.

2-5. *Steps to Enhancing Communication*, Alzheimer’s Disease and Related Disorders Association, Inc., 1997

Resources And Further Reading

1. *“Home Is Where I Remember Things:” A Curriculum for Home and Community Alzheimer Care*, by Lisa P. Gwyther, Duke University Medical Center, Durham, North Carolina, 1997. To order, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871, or visit our web site at www.mainealz.org
 2. *Caring for People With Dementia: A Training Guide*, published by The Training Collaborative, a joint project of the Alzheimer’s Association, Maine Chapter; the Alzheimer’s Care Center, Gardiner; Muskie School of Public Service at the University of Southern Maine; and the Maine Alzheimer’s Project, April 1998. For more information, contact the Maine Alzheimer’s Association at 1-800-660-2871.
 3. *Caregiving at a Glance: Fingertip Help for Families Taking Care of People With Alzheimer’s Type Illnesses*, (Second Edition), by Lin E. Noyes, Family Respite Center, Falls Church, Virginia, 2000. To order, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871, or visit our web site at www.mainealz.org
- ➔ You can also order the following brochure by calling the Maine Alzheimer’s Association toll-free at 1-800-660-2871.
- *Steps to Enhancing Communication: Interacting With Persons with Alzheimer’s Disease*, Alzheimer’s and Related Disorders Association, 1997.

Appendix 3.1

Communication Guidelines

Get the resident's attention before speaking

- Approach from the front, slowly
- Get on the same level or height as the resident
- Maintain eye contact
- Say the resident's name; use gentle touch, as appropriate and tolerated.

Set a good tone

- Use a calm, gentle, matter-of-fact approach
- Speak with a low-pitched, reassuring tone of voice
- SMILE
- Introduce yourself, no matter how obvious it seems
- Start with social conversation to relax the resident and gain his or her trust before moving on to the task
- If you leave the room or are interrupted, start over.

Slow down

- Expect things to take longer; the resident is doing the best that he or she can with an impaired memory
- Don't act rushed or impatient
- Give the resident plenty of time to respond to a question or request
- If you need to repeat information, do so using the same words as before.

Simplify

- Speak clearly and distinctly
- Use short, concrete, familiar words and proper names for people and objects
- Communicate one idea or task at a time
- Use nonverbal gestures to demonstrate what you want him or her to do.

Reassure

- Talk the resident through the situation
- Ask him or her to help
- Use gentle humor
- Reassure and praise frequently.

Pitfalls to avoid

- Talking louder
- Arguing, reasoning, giving long explanations, and reality orientation
- Commands (Do "with," not "to") and negative language (e.g., "No." "Don't.")
- Talking down to the resident as if to a small child, or talking about the resident as if he or she is not there.

Be patient and kind. Focus on the resident, not the disease.

Chapter 4

Dealing with Challenging Behaviors

We all have behaviors. Behaviors are demonstrations of who we are and how we communicate our response to daily living.¹

Five General Principles About Behavior

- 1. Behavior varies from person to person.** While it is possible to list behaviors that are common to dementia, it is not possible to predict which, if any, behavior a particular resident will display in the course of his or her illness. Some people display traits that are exaggerated versions of their former personality (e.g., a former boxer who becomes more aggressive) while others do things that seem entirely out of character (e.g., the minister's wife who is swearing like a pirate). People have good days and bad days and behaviors will fluctuate accordingly. Behaviors will also change as the disease progresses.
- 2. Loss of control is not deliberate.** People with Alzheimer's disease are capable of a full range of behaviors — positive to negative— just as we all are. Due to the damage to their brains, however, they do not have the same ability to plan, initiate, and control the behaviors that they display. People with Alzheimer's are not being deliberately difficult or manipulative, and they are not trying to drive you crazy! These residents are simply reacting in the moment to their feelings and to the world around them. They are doing the best they can with a disabling disease.
- 3. Behavior does not occur in a vacuum.** Behaviors displayed by residents with dementia are related to the loss of cognitive capacities and are often triggered by internal distress or something in the environment that is causing fear, confusion or frustration.
- 4. Behavior is communication.** As verbal skills diminish, behavior becomes the resident's primary mode of communication. Therefore, always ask: "What is the behavior saying about the resident's thoughts, feelings, and perceptions that he or she cannot express in words?" Is she in pain? Frightened? Confused? Is there an unmet need? For example, pacing or anxious, repetitive speech may mean that the resident is hungry or needs to go to the bathroom.

Continued

5. **Positive approaches work best.** Use a friendly, reassuring, helpful approach that respects the resident with dementia as an adult. Negative approaches such as demands, threats or scolding will not be effective and may provoke a catastrophic reaction, making a difficult situation even worse.

Behaviors Common to Dementia

- Repetitive speech or actions
- Neglect of personal hygiene and grooming
- Swearing or tactlessness
- Wandering
- Sundowning (increased restlessness or agitation at the end of the day)
- Shadowing (following others)
- Apathy or withdrawal
- Hostility or aggression
- Hoarding
- Sleep disturbances
- Paranoia and suspiciousness (e.g., false accusations about people stealing from them)
- Delusions (beliefs that are contrary to fact)
- Hallucinations (false perceptions of something that is not really there)
- Decreased awareness of personal safety
- Forgetting what is private behavior (e.g., urinating in a plant pot, cleaning dentures at the table, disrobing or masturbating in public)
- Catastrophic reactions (extreme emotional responses such as yelling, crying or striking out that seem out of proportion to the actual event)

Source: Alzheimer's Disease and Related Disorders Association, Inc.
1999

Possible Causes of Challenging Behaviors²

Physical Causes

- Effects of medication
- Impaired vision or hearing
- Acute illness (e.g., urinary or respiratory infection)
- Chronic illness
- Pain or physical discomfort
- Constipation
- Dehydration
- Fatigue

Emotional Causes

- Depression
- Fear
- Frustration
- Embarrassment
- Unable to communicate needs or articulate feelings.

Environmental Causes

- Environment too large
- Too much clutter
- Excessive stimulation (too loud, bright, everyone talking at once)
- Too little stimulation (bored, lonely)
- No orientation information or cues (e.g., all doors look the same on the hallway)
- Too many choices or ideas at once
- Unstructured or unfamiliar environment

Task-Related Causes

- Too complicated
- Too many steps combined
- Task unfamiliar; requires new learning

Responses To How Individual Is Approached Or Treated

- Hurrying or rushing
- Impatience
- Being preoccupied; not focusing on the resident
- Quizzing with memory questions
- Commands
- Talking loudly
- Negative demands (“No,” “Don’t,” “Can’t,” “Should”)
- Criticizing, scolding, shaming
- Trying to argue or convince
- Long explanations
- Reality orientation

- Talking down to the resident or talking about them as if they were not there.

The Parable of the Lighthouse

Collision: A True Log

Signalman Alpha: This is Signalman Alpha. Please divert your course fifteen degrees to port to avoid imminent collision....

Signalman Bravo: This is Signalman Bravo. Recommend you come right fifteen degrees to avoid imminent collision....

Signalman Alpha: This is Signalman Alpha. We are a large naval vessel. I say again, change course to avoid collision...

Signalman Bravo: This is Signalman Bravo. I repeat, change course to starboard immediately.

Signalman Alpha: This is the Captain of the aircraft carrier USS Enterprise, a 75,000-ton United States Naval warship. Get out of the way, now!

Signalman Bravo: This is a lighthouse keeper. Your call.

Author Unknown

Problem Solving Strategies

Ask questions

- What exactly is the behavior?
- What was happening just before the behavior occurred?
- When does it happen? Early morning? Late afternoon?
- How often has it happened?
- Where does it happen? In the lobby? The hallway? The lounge?
- Why is the behavior a problem? For whom?
- How was the behavior handled? Did it work? Keep a Log

Keep a log

- Document the behavior responding to the questions above.
- See if you can determine a pattern.

Look for triggers

- the resident's physical condition
- the resident's emotional condition
- the environment
- the task
- the way the resident was approached by others.

Step into the resident's shoes

- Try to see the situation from the resident's perspective.

Pay attention to nonverbal cues

- Be sensitive to the resident's mood, facial expression, tone of voice and body language.

Explore potential solutions

- Alert the Resident Service Coordinator or Property manager to the situation.
- Talk to the resident.
- Use good communication skills when approaching the resident [see Chapter 3].
- Try to get the resident to agree to a medical evaluation or a home nursing visit to determine the cause of the dementia and to rule out physical or medical problems that may be creating an excess disability.
- Proceed with steps for emergency and non-emergency situations as outlined in Chapter 6.
- Consider modifying the resident's environment to make it easier for him or her to manage (e.g., an automatic shut-off for the stove or a dark-colored toilet seat).
- Sponsor an education session about memory loss and dementia for the whole building in order to foster a more tolerant community.
- Call the Maine Alzheimer's Association's Helpline (1-800-660-2871) for help in brainstorming possible solutions and referral sources.
- Refer the resident to appropriate supportive services.
- Involve Adult Protective Services if the resident is at risk due to abuse, exploitation or self-neglect.
- Begin to explore alternative living arrangements if the resident's needs can no longer be met in independent housing.

Tips For Responding To The Resident With Dementia

- ➔ Stay calm and be understanding. Remember: the resident will mirror your mood.
- ➔ Acknowledge feelings. “*You seem upset about . . .*” “*You’re thinking about . . .*” or “*You’re missing your mother . . . your home,*” etc. Then encourage venting or reminiscing.
- ➔ Reassure: “*It’s okay. I’ll help you.*”
- ➔ If the resident begins to get upset, change the subject and distract his/her attention to something else. (e.g, “*What beautiful flowers. You must have a green thumb.*”)
- ➔ Ask the resident to help you.
- ➔ Look for reasons for the behavior [see page 53].
- ➔ Accept the behavior as a reality of the disease and try to work through it.
- ➔ Explore various solutions.
- ➔ Be patient and flexible.
- ➔ Acknowledge requests and respond to them.
- ➔ Find other outlets for the behavior.
- ➔ Encourage the use of memory aides (notes, reminders, calendars) whenever feasible.
- ➔ Do not argue or try to convince.
- ➔ Do not take behaviors personally.
- ➔ If the resident accuses you of stealing, don’t argue and don’t take the behavior personally. False accusations are not uncommon because people with dementia can’t remember where they leave their belongings and may misinterpret the statements and actions of those around them. Be calm and reassuring. Respond to the feelings behind the statement and offer to help look for the item. “*You must be very upset. Let’s look for your purse.*” Take another person along whenever you enter the resident’s apartment.

Strategies For Specific Behaviors

The suggested coping strategies in the Appendices that follow have been compiled from a number of sources, including Alzheimer's Association brochures and training materials, newsletters, books and articles. For the most part, these strategies are geared for family caregivers, or for professional staff providing direct care. Housing staff may want to bear in mind the following:

- When it comes to challenging behaviors, there is no cookbook or magic formula. Finding a solution that works for a particular individual in a particular situation is largely a matter of trial and error.
- Even when a solution is found it may not work every time. And, in any event, adjustments will need to be made as the disease progresses and new behaviors present themselves.
- While housing staff are not family, neither are they direct-care providers. However, these strategies represent accepted practice in the dementia care community. These are approaches that accept the reality of the disease rather than attempting to change the resident. They seek to prevent or minimize problems while respecting the resident and supporting his or her remaining strengths. We invite and encourage housing staff to review these suggestions and adapt and apply them in ways that are consistent with the regulations governing your own setting and job description.

Sources

1. *Alzheimer's Disease: Activity-Focused Care* (Second Edition), by Carly R. Hellen, Butterworth-Heinemann, Boston, 1998. Page 295.
2. *Understanding Difficult Behaviors*, by Anne Robinson, et. al., Geriatric Education Center of Michigan, Eastern Michigan University, 1996.
3. Adapted from: *Steps to Understanding Challenging Behaviors*, Alzheimer's Disease and Related Disorders, Association, Inc., 1996.

Resources And Further Reading

1. *“Home Is Where I Remember Things:” A Curriculum for Home and Community Alzheimer Care, Home and Community Alzheimer Care*, by Lisa P. Gwyther, Duke University Medical Center, Durham, North Carolina, 1997. To order, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871 or visit the web site at www.mainealz.org
 2. *The 36-Hour Day* (Third Edition), by Nancy L. Mace and Peter V. Rabins, The Johns Hopkins University Press, Baltimore, 1999. To order, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871, or visit the web site at www.mainealz.org
 3. *Understanding Difficult Behavior: Some Practical Suggestions for Coping with Alzheimer’s Disease and Related Illnesses*, by Anne Robinson, et al., Geriatric Education Center of Michigan, Eastern Michigan University, 1989. To order, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871, or visit the web site at www.alz.org
 4. *Caregiving at a Glance: Fingertip Help for Families Taking Care of People With Alzheimer’s Type Illnesses*, (Second Edition), by Lin E. Noyes, Family Respite Center, Falls Church, Virginia, 2000. To order, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871, or visit the web site at www.alz.org
 5. *Caring for People With Dementia: A Training Guide*, published by The Training Collaborative, a joint project of the Alzheimer’s Association, Maine Chapter; the Alzheimer’s Care Center, Gardiner; Muskie School of Public Service at the University of Southern Maine; and the Maine Alzheimer’s Project, April 1998. For more information, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871.
 6. Alzheimer’s Awareness Training Packet, developed by Evelyne Tunley-Daymude, Ph.D., Director of Education, Alzheimer’s Association Alaska Chapter. For more information, call 1-800-478-1080.
 7. *Alzheimer’s Disease: Activity-Focused Care* (Second Edition), by Carly R. Hellen, Butterworth-Heinemann, Boston, 1998. To order, contact the Maine Alzheimer’s Association toll-free at 1-800-660-2871, or visit the web site at www.alz.org
 8. *Behaviors in Dementia: Best Practices for Successful Management*, edited by Mary Kaplan and Stephanie B. Hoffman, Health Professions Press, Baltimore, 1998.
- ➔ You can also order the following brochure by calling the Maine Alzheimer’s Association at 1-800-660-2871.

- *Steps to Understanding Challenging Behaviors*

Appendix 4.1

Bathing: Tips for Families and Direct Care Providers

Keeping the Alzheimer's resident clean and well groomed can be a challenge. A depressed resident might have lost her desire to bathe while another resident might feel embarrassed about getting undressed or might become frightened by running water or mirrors.

For the resident with Alzheimer's, it's easy to feel confused and overwhelmed by simple daily routines such as bathing and grooming. If the resident seems afraid, stressed or resistant to bathing, try to determine the reasons why by asking the following questions:

Physical/Psychological Factors

- Does the resident seem depressed?
- Is there a physical illness or infection?
- Does the resident seem overly sensitive to water or changes in water temperature?

Environmental Factors

- Is the resident sensitive about having someone else in the bathroom?
- Is the resident able to find the bathroom and see clearly once he or she enters it?
- Is the room temperature too cold?
- Is the water temperature too hot or cold? Or is the water pressure too intense? Is the water in the tub too deep?

Special Concerns

- Is the resident afraid of falling, running water or soap?
- Or is the resident confused over such tasks as turning on the water or filling the sink?

Once you've determined the answers to these questions, you'll be in a better position to manage the bathing routine.

Action Steps

➔ Have reasonable expectations

Keep in mind that frequency of washing and bathing is a personal preference. Some people may not feel the need to shower and/or wash their hair every day. In these cases you might want to alternate a sponge bath with a more complete bath or shower.

Continued

➔ **Adapt to the resident's needs, routines, and preferences**

If the resident is used to taking a shower in the morning or a bath at night, try to maintain that routine. Changing from day to night might distress the resident. Also keep in mind that a resident may refuse to take a bath for an unfamiliar caregiver of the opposite sex.

➔ **Prepare the bathroom in advance**

- Have the towels ready.
- Draw the water in the bathtub and test the temperature.
- Pre-measure the shampoo.
- Develop a soap pocket in the washcloth so that the resident can wash him or herself.
- Keep the bathroom warm and comfortable.

➔ **Gently prepare the resident for the bath**

Be directive at bath time by using such phrases as, "Your bath is ready." In this way, the resident will focus on each step of the task instead of whether or not she needs or wants a bath. If the individual continues to resist the idea of bathing, distract her for a few moments and then try again.

➔ **Make the bathroom safe**

- Always check the temperature of the water. Keep in mind that the resident may not be able to judge temperature.
- Avoid using bubble bath or bath and shower oils that would make the tub or shower stall slippery.
- Keep in mind that to people with Alzheimer's disease, showers are often more dangerous and frightening than baths. If you must use a shower, install grab-bars and use a tub seat.
- Never leave a resident alone in the bath or shower.
- Consider using a hand-held shower.
- Use only two to three inches of water in the tub and make sure there are rubber mats or decals on the tub's bottom.
- Use a non-slip bath mat and make sure that the bathroom floor is free from puddles. Some caregivers install carpeting in the bathroom.

➔ **Take care in giving the bath**

- Gently coach the resident during each step of the bath, reminding her of the areas that need washing. Keep in mind that you may need to complete part of the bath or shower yourself.
- Plan to do a project such as hair washing in the morning when the resident is well rested. Get the individual to participate as much as possible.
- Avoid using harsh deodorant soaps unless there's a serious problem with incontinence, in which case there are special soaps available.

Continued

- Make sure that the resident washes the genital area, especially if incontinence is a problem. Also make sure that the resident washes within folds of flesh and under the breasts.
- After the bath or shower is completed, check to see that the resident is completely dry.
- Check the resident for red areas of skin, rashes and sores. If the problem is serious, consult a physician. Keep in mind that pressure sores and skin ulcers can develop quickly on people who sit or lie down much of the time.
- Use a body powder, cornstarch or baby powder under the breasts or in creases or folds of the skin, and use a lotion to keep skin soft and flexible. If the individual resists deodorant, try baking soda.

Appendix 4.2

Combativeness: Tips for Families and Direct Care Providers

When an Alzheimer's resident becomes combative, angry or agitated, it may be because of frustration. The resident may feel that he or she is being pushed to do something that simply can't be done. Consider the following factors as possible sources of frustration:

Dressing

- The resident who can't get an arm through a sweater may grow increasingly upset and start to thrash around.

Bathing

- The resident who's frightened by running water in the bathtub may push away a caregiver who is trying to give him or her a bath.

Eating

- The resident who doesn't like a certain type of food may refuse to eat it.

Keep in mind that combativeness takes many forms. Sometimes the resident may simply try to push your hand away, while at other times the resident may resist or strike you. Deal with combativeness by trying to examine the underlying causes. Consider the following issues:

Physical Causes

Is the resident tired because of inadequate rest or sleep? Are medications such as sedatives and tranquilizers creating side effects? Is the resident unable to express the fact that he or she is in pain?

Environmental Causes

Is the resident overstimulated by loud noises, people or physical clutter? Is the environment unfamiliar? Does the resident feel lost or abandoned by the caregiver?

Poor Communication

Are you asking too many questions or making too many statements at once? Are your instructions simple and easy to understand? Is the resident picking up on your own stress and irritability? Are you making the resident more frustrated by being overly negative or critical?

Continued

Action Steps

➔ Be on the lookout for frustration

Look for early signs of frustration in such activities as bathing, dressing or eating, and respond in a calm and reassuring tone.

➔ Don't take aggression and combativeness personally

Keep in mind that the resident isn't necessarily angry at you. Instead, he or she may misunderstand the situation or be frustrated with his or her own disabilities.

➔ Avoid teaching

Offer encouragement, but keep in mind the resident's capabilities and don't expect more than he or she can do. Avoid elaborate explanations or arguments.

➔ Use distraction

Don't persist in making the resident perform a particular task, especially if he or she has repeatedly been unsuccessful. If you see the resident getting frustrated with buttoning a shirt, try to distract her with another activity such as putting on a pair of pants. After a time, you can return to the shirt. Or take the resident to a quiet room, have a cup of tea or go for a walk.

➔ Communicate directly with the resident

Avoid expressing anger or impatience in your voice or physical actions. Instead use positive, accepting expressions such as "please," "thank you," and "don't worry, everything's going to be fine." In addition, use touch to reassure and comfort the resident. For example, you might want to put your arm around the resident or give him or her a kiss. In addition, follow these tips:

- Speak slowly and clearly.
- Use short, simple sentences.
- Approach the resident slowly and from the front.
- Use repetition and frequent reminders.

➔ Decrease your level of danger

Assess the level of danger, both for yourself and for the resident. In other words, if the resident becomes combative, ask this question: "How much trouble am I in--and what can I realistically do about it?" Often you can avoid harm by simply taking five steps back and standing away from the resident for a short period of time. On the other hand, if the person is headed out of the house and onto a busy street, you need to be more aggressive.

Continued

➔ **Be conservative in using restraint or force**

Unless the situation is serious, try to avoid physically holding or restraining the resident. By fighting with the individual, you'll probably make him even more frustrated and anxious.

➔ **Experiment with objects that have a soothing effect**

Some caregivers believe that stuffed animals have a soothing effect on the resident, while others find that pets—from cats and dogs, to birds or goldfish—have a calming effect.

➔ **Learn from previous experiences**

Try to avoid situations or experiences that make the resident combative. For example, if the resident tires easily when he or she visits with family members, you might want to limit the length of these visits. Try to identify early signs of agitation. For example, outbursts are sometimes preceded by restlessness, frustration, fidgeting, or blushing.

➔ **Restructure tasks and the resident's environment**

- Simplify tasks or plan more difficult tasks for the time of the day when the resident is at his best.
- Give the resident adequate time to respond to your directions or requests.
- Allow the resident to make some choices, but limit the total number of choices. Having too many decisions to make about what to eat or wear might be confusing or overwhelming.
- Break down each task into small steps and allow the resident to complete one step at a time.
- Keep the environment calm, quiet and clutter free.

Appendix 4.3

Hallucinations: Tips for Families and Direct Care Providers

Understanding the difference between hallucinations and delusions is important. A delusion is defined as a false idea, sometimes originating in a misinterpretation of a situation. For example, an elderly resident with a delusion may think that family members are stealing from her or that she's in another place when she's actually still in her own home.

A hallucination, in contrast, is a false perception of objects or events, and is sensory in nature. When a resident with Alzheimer's has a hallucination, he or she can see, hear, smell, taste, or even feel something that isn't really there.

Hallucinations are caused by changes within the brain that result from Alzheimer's disease. Hallucinations are visual and auditory. For example, a resident may see the face of a former friend in a curtain or see insects crawling on his hand. In other cases, he may hear someone talking and may even talk back to the imagined person.

Hallucinations can be frightening to the resident and the caregiver. On some occasions, the resident may see threatening images or just ordinary images of people, situations or objects from the past. Although you can create an environment to manage wandering, you won't be able to control the resident's hallucinations or prevent them from occurring. Some ideas to follow for handling a resident with hallucinations are:

Action Steps

➔ Obtain medical guidance

- Ask a physician to evaluate the resident to determine if medication is needed or might be causing the hallucinations. In some cases, hallucinations are caused by schizophrenia, a disease different from Alzheimer's.
- Have the resident's eyesight or hearing checked or make sure that the resident wears her glasses or hearing aid on a regular basis.
- The physician can look for physical disorders such as kidney or bladder infections, dehydration, intense pain, or alcohol or drug abuse. These are conditions that might cause hallucinations. If the physician prescribes a medication, watch for symptoms such as over-sedation, increased confusion, tremors or tics.

Continued

➔ **Assess and evaluate**

Assess the situation and determine whether or not the hallucination is a problem for you or for the individual. Is the hallucination upsetting to the resident? Is it leading him or her to do something dangerous? Does the sight of an unfamiliar face cause the resident to become frightened? If so, react calmly and quickly with reassuring words and comforting touch.

➔ **Respond with caution**

Be cautious and conservative in responding to the resident's hallucinations. If the hallucination doesn't cause problems for you, the resident or other family members, you may want to ignore it. Don't argue with the resident about what she sees or hears. Unless her behavior becomes dangerous, you might not need to intervene.

➔ **Offer reassurance**

Reassure the resident with kind words and a gentle touch. For example, you might want to say: "Don't worry. I'm here. I'll protect you. I'll take care of you," or "I know you're worried. Would you like me to hold your hand and walk with you for awhile"

- Gentle patting may turn the resident's attention toward you and reduce the hallucination.
- Look for the reasons or feelings behind the hallucination and try to find out what the hallucination means to the individual. For example, you might want to respond with words such as these: "It sounds as if you're worried" or "I know this is frightening for you."

➔ **Use distraction**

Suggest that the resident come with you on a walk or sit next to you in another room. Frightening hallucinations often subside in well-lit areas where other people are present.

- You might also try to turn the resident's attention to other features of the room. Other distractions include music, conversation, drawing, looking at photos or pictures, or counting coins.

➔ **Respond honestly**

Keep in mind that the resident may sometimes ask you about the hallucination. For example, "Do you see him?" or "Can you hear the children laughing?" You may want to answer with words such as these: "I know that you see something, but I don't see it." In this way, you're not denying what the resident sees or hears or getting involved in an argument.

Continued

➔ **Check out the reality of the situation**

Ask the resident to point to the area where he sees or hears something. Glare from a window may look like snow to the resident and dark squares on a tiled floor may look like dangerous holes.

➔ **Modify the environment**

If the resident looks at the kitchen curtains and sees a face, you may be able to remove, change or close the curtains.

- Check the environment for noises that might be misinterpreted, for lighting that casts shadows, or for glare, reflections or distortions from the surfaces of floors, walls, and furniture.
- If the resident insists that he or she sees a strange person in the mirror, you may want to cover up the mirror or take it down. It's also possible that the resident doesn't recognize himself or herself.
- On other occasions, you may want to turn on more lights and make the room brighter.

You can ease the fears of the resident with Alzheimer's disease by using words that are calm, gentle and reassuring. Remember that the hallucination is very real to the individual with the disease. Your goal is to support the resident's feelings without agreeing with the hallucination.

Appendix 4.4

Coping with Suspicion and Paranoia: Tips for Families and Direct Care Providers

“You stole my purse! It was right here! Get away from me! Leave me alone! I hate you!” These words may be all too familiar to caregivers, families and friends of individuals with Alzheimer’s disease or related disorders. Suspiciousness is very common in people who suffer from dementia. Some even project their own feeling of frustration and hostility onto another person, something known as “paranoia.” The uncertainty, loss of control and confusion experienced by those with dementia contributes to this most upsetting type of behavior.

What Causes It?

Think about it . . . if you had difficulty recognizing people, you might approach them cautiously. If you were self-absorbed, you might assume that conversations you overheard were about you. When you have difficulty understanding things, it is easy to become worried, scared and suspicious.

These tendencies often lead to accusations, angry outbursts, and even delusions (thoughts that are contrary to reality) or hallucinations (seeing, hearing, or sensing things that are not really there).

Suspiciousness and paranoia may be some of the most difficult behaviors to witness in a loved one.

Check Potential Causes

- Visual problems or hearing loss may result in hearing or seeing things.
- Insufficient lighting may play tricks.
- Unfamiliar noises or changes in the surrounding may account for fear.
- Physical illnesses, infections, medication or dehydration may be to blame. Watch for any signs of pain. Increase your vigilance to be sure that your loved one is not eating or imbibing anything inappropriate.
- The source of suspicion may be real! Check it out first.
- Memory loss may lead to the sensation that something is wrong, leading to frustration when the resident cannot explain or name the difficulty.

Continued

- Assess the problem. What happened right before the resident became suspicious? Has something like this happened before? Was it in the same room or at the same time of day?

Action Steps

- ➔ Reassure and comfort with a gentle touch by holding and by using calming words and gestures. For example, “Don’t worry. I’ll help you find it. It’s all right to feel that way.”
- ➔ Focus on and acknowledge the feelings surrounding the situation rather than arguing or reasoning. “You’re feeling afraid (angry). I understand how upsetting this is. This is very frightening for you, isn’t it?”
- ➔ Take the resident’s mind off the problem by using familiar distractions. Take a walk; turn on some music; bring out a favorite activity, photo album or game.
- ➔ Accept the resident’s belief that this is happening rather than arguing or challenging. “I see that your glasses are not right here. Let’s look for them.”
- ➔ When you have identified possible environmental causes, change the surroundings.
- ➔ Cover mirrors if they cause confusion. Many people with dementia do not recognize their own images.
- ➔ Brighten the room.
- ➔ Restore furniture to its original placement if it has been moved.

When There Are Accusations Of Stealing . . .

- Help the resident look for lost objects rather than scolding.
- Keep a spare set of frequently lost items.
- Identify places where valuables are stored and keep track of favorite hiding places.

What About Medications?

Obtain advice about medication from a physician.

Appendix 4.5

Incontinence Tips for Families and Direct Care Providers

Incontinence, which includes loss of bladder and/or bowel control and bedwetting, is a difficult problem if you're caring for an Alzheimer patient. Incontinence is common among Alzheimer patients--especially those in the latter stages of the disease.

Although you can manage incontinence by changing the patient's routine, clothing or environment, at some point you'll need to accept incontinence as a permanent condition of the disease.

If incontinence is a new behavior, your first and most important step is to identify the possible reasons for this loss of control. Ask yourself the following questions:

Medical Conditions

Could the reason be medical? For example, could the resident have a urinary tract infection, constipation, or a prostate problem? Or is there an illness such as diabetes, stroke, or Parkinson's disease? Do movement difficulties make it hard for the resident to get to the bathroom in time? If the answer to any of these questions is "yes," you may want to consult with his or her physician.

Stress

Is the incontinence caused by stress or movement? For example, does the resident release urine with a sneeze, cough or laugh? Does fear of an embarrassing accident make the resident want to continually visit the bathroom? Keep in mind weak pelvic muscles in a woman could cause uncontrollable loss of urine.

Medication

Is the resident on medication that might intensify the behavior? Is it possible that tranquilizers, sedatives, or diuretics contribute to incontinence? Keep in mind, for example, that some tranquilizers can relax the bladder muscles. Medications used to treat incontinence can cause such side effects as dry mouth and eye problems.

Dehydration

Did anyone withhold fluids when the resident started to lose bladder control? If so, the resident might become dehydrated. Dehydration can, in turn, create a urinary tract infection, which can lead to incontinence.

Continued

Diuretics

Are you giving the resident fluids that might produce a diuretic effect (increased urinating)? Beverages such as coffee, colas, and tea might contribute to incontinence.

Environment

Are there problems in the environment? Is it possible that the resident can't find the bathroom? Does the resident have to travel too far to reach the bathroom in time? Is the resident afraid of falling? Are there obstacles in the path such as chairs or throw rugs? Is the path well lighted?

Clothing

Does the resident have problems undressing in the bathroom? Are the zippers and buttons on clothing causing problems?

ACTION STEPS

➔ Innovate

Be willing to experiment with new concepts and ideas. Keep in mind that every person is different. What works for one person may not work for another.

➔ Understand

Remember that accidents are embarrassing. Be matter-of-fact and understanding and avoid blaming or scolding the individual. When the resident is successful, use praise, encouragement and reassurance.

➔ Communicate

Encourage the resident to tell you when she thinks she needs to use the bathroom. The resident may not be able to say, "I need to use the bathroom." Watch for visible cues that the resident needs to use the bathroom. For example, the resident may get restless, make unusual sounds or faces, or pace around the room.

➔ Plan ahead

Train yourself to respond to the resident's routine and schedule. Identify when accidents occur and plan ahead. If an accident happens every two hours, you'll need to get the resident to the bathroom before that time. You might also find it helpful to keep a notebook or log that notes when the person uses the bathroom.

Continued

➔ **Change and adjust**

Be patient and allow the resident adequate time in the bathroom. In addition, rearrange the environment to make it easier for the resident to use the bathroom. For example, leave on a nightlight in the bathroom and bedroom. Put a picture of a toilet on the bathroom door, or paint the bathroom door a color different than the wall. If accidents occur at night, consider a portable commode or urinal near the bed.

➔ **Simplify clothing**

Keep the resident's dress simple and practical. Instead of choosing clothing with zippers and buttons, choose easy-to-remove and easy-to-clean styles such as sweat pants with elastic waistbands. Consider using such products as pads or protective bedding, adult diapers, or panty liners for female patients.

➔ **Follow-up**

Make sure the resident uses the bathroom. You may need to assist in removing clothes, wiping or flushing. You might also want to stimulate urination by giving the resident a drink of water or running water in the sink. Keep sensitive skin areas clean with regular washing and application of a powder or ointment.

➔ **Control**

To help control night incontinence, limit the resident's intake of liquids after dinner and in the evening and cut down on drinks such as cola, coffee, tea, and grapefruit juice. Encourage the resident to drink at least one-and-a-half quarts (six cups) of fluids daily. For variety, you might want to introduce decaffeinated herbal teas, decaffeinated coffee, jello, or fruit juice.

Help the resident with Alzheimer's retain a sense of dignity despite the problems with incontinence. Reassuring and non-judgmental statements will help lessen feelings of embarrassment.

Appendix 4.6

Sundowning and Shadowing **Tips for Families and Direct Care Providers**

Sundowning

People with diseases such as Alzheimer's often have behavior problems in the late afternoon and evening. They may become demanding, suspicious, upset or disoriented, see or hear things that are not there and believe things that aren't true. Or they may pace or wander around the house.

While experts are unsure how or why this behavior occurs, they suspect that the problem of late afternoon confusion, which is sometimes called "sundowning," or "sundown syndrome," may be due to these factors:

- The resident with Alzheimer's can't see well in dim light and becomes confused.
- The impaired resident may have a hormone imbalance or a disturbance in his/her "biological clock."
- The resident with Alzheimer's tires at the end of the day and is less able to cope with stress.
- The resident is involved in activities all day long and grows restless if there's nothing to do in the late afternoon or evening.
- The caregiver communicates fatigue and stress to the resident with Alzheimer's and the resident becomes anxious.

ACTION STEPS

➔ Try these ways to lesson the behaviors of "sundowning":

- Make afternoon and evening hours less hectic. Schedule appointments, trips, and activities such as baths or showers early in the day.
- Help the resident to use up extra energy through exercise. For the resident who tends to pace or wander in the evening, you may want to arrange at least one or two brisk walks during the day.
- Control the resident's diet. Reduce foods and beverages with caffeine (chocolate, coffee, tea, and soda) or restrict them to the morning hours to reduce agitation and sleeplessness.

Continued

- An early dinner or late afternoon snack may also help.
- It's important to provide regular activities and you may want to discourage napping during the day if nighttime sleeplessness is a problem.
- You may want to reduce the level of noise from radios, televisions or stereos, control the number of people who visit in the evening hours, or confine noisier family activities to another area of the house.
- Consult with your physician. Your physician may be able prescribe medication to encourage sleep. At the same time, your physician can check for signs of depression, or for physical problems, such as prostate difficulties that might lead to frequent urination. This condition can cause pain and make sleep uncomfortable.
- Make it easy for the resident to use the bathroom. Consider a bedside urinal or commode. Or encourage the resident to use the bathroom before going to bed.
- Keep rooms adequately lit. Good lighting may reduce the resident's confusion. A night-light may prevent the resident from becoming agitated in unfamiliar surroundings.

➔ **Remain flexible and consider the resident's needs.**

- While people with Alzheimer's may find it difficult to sleep in their beds, they may fall asleep more easily on the living room couch or in a reclining chair.
- Reassure and comfort the resident. Tell the resident experiencing sundowning what time it is and what's going on in the house. Let the resident know you're there and will remain there. Then try to involve the resident in a meaningful activity such as setting the table, folding towels, doing dishes, or sweeping the floor.
- Avoid arguing or asking for explanations. The resident may not know what's wrong or be able to tell you if he does. Keep in mind that the resident with Alzheimer's has no control over annoying, repetitive behavior. Confusion and restlessness occur because the brain can no longer sort out cues in the environment.

➔ **Remember to care for yourself.**

- Make sure you get adequate rest. Just because the resident with Alzheimer's can't sleep at night doesn't mean you should go without sleep. Arrange for another family

member to supervise the resident at night. Or arrange the room so that it is safe enough (and has locked doors) to let the resident stay awake and pace there while you nap or sleep in another room.

Continued

Shadowing

"Sundowning" is often accompanied by "shadowing," where the resident with Alzheimer's follows or mimics the caregiver, or talks, interrupts, and ask questions repeatedly. At times, the resident may become upset if the caregiver wants to be alone. While shadowing and other forms of agitation vary from resident to resident, you may be able to manage the behavior by following these steps:

ACTION STEPS

➔ Examine factors that encourage agitation. Consider these questions:

- How long does the behavior last?
- At what time of day does it occur?
- Is the behavior triggered by certain people or surroundings?
- What seems to calm the impaired resident?

Once you develop answers to these questions, you may be able to avoid the situations that bring about agitation and introduce activities that help calm the resident with Alzheimer's.

- ✓ Protect your privacy. You may want to install a childproof doorknob on the bathroom door or use a timer and reassure the resident by saying, "I'll be back when the timer goes off."
- ✓ Try to keep the resident occupied. Find simple, repetitious activities to occupy the resident even if you could do them better on your own. Possibilities include folding the wash, dusting, stacking papers or magazines, stuffing envelopes, or winding a ball of yarn. Or provide the resident with Alzheimer's with headphones for listening to calming music.
- ✓ Consider "gum therapy" or "cereal therapy." If the resident with Alzheimer's is able to chew and swallow easily, you may want to give him/her sugarless gum. Or consider providing the resident with a non-breakable bowl of high-fiber, low-sugar cereal. By having something to snack on, the resident may be less inclined to talk or ask questions.
- ✓ Rely on the ideas of support groups. Caregivers are always discovering new ways to deal with behaviors such as shadowing and sundowning and are happy to share them.

A better understanding of the feelings of the resident with Alzheimer's disease, such as fear, frustration, and anger, may help you accept the resulting behaviors. Providing

reassurance and helping your loved one respond to his or her changing environment can help you manage the resident's behavior.

Chapter 5

Safety: Issues and Tips

Initially, people with Alzheimer's disease or related dementias may compensate for their worsening memory by avoiding difficult activities or situations, being extra cautious, or by using various memory aides such as notes and calendars to remind them of what they have already done or what they must do next. Eventually, however, problem-solving skills erode. With some care and creativity, however, steps can be taken to enhance the resident's safety and prolong their ability to live independently.

Why Is Safety A Concern?

As their memory worsens and judgment and thinking become impaired, memory-impaired residents may fail to recognize safety risks to themselves and others (e.g., eating spoiled food or forgetting to turn burners off). They may wander away from home and get lost. They may become targets for abuse or exploitation by others. This chapter identifies common safety issues and suggests steps that housing staff can recommend to the resident and/or family or paid caregivers.

Observable Signs That Safety Is Becoming A Problem

Concerns about self-care and protection

- Neglects grooming and personal hygiene
- Forgets to take medications or taking them improperly
- Dresses in attire is inappropriate for weather/season
- Loses weight: doesn't seem to be shopping for food or eating
- Suffers from vomiting or diarrhea as a result of eating spoiled food or inedible items
- Has trouble with balance, shuffling gait
- Seems fearful or uncertain when navigating steps, thresholds, dark or patterned floors
- Becomes careless about locking door, letting strangers into building
- Experiences trouble with money (overdue or overpaid rent, utilities shut off, etc.)
- Ignores non-compliance or eviction notices.

Concerns in the home

- Causes repeated fire safety issues: burns pans, sets off fire alarm, careless with cigarettes
- Exhibits extreme clutter and hoarding
- Disposes of odd or inappropriate items in the trash

- Lets water overflow in sinks or tub

Wandering

- Is frequently unable to find own apartment
- Follows other people
- Walks uninvited into other people's apartments
- Rides on the bus for hours; forgets which stop they need
- Gets lost away from home and is returned home by police.

Driving

- Repeated fender benders
- Can't find own car in parking lot
- Gets lost in familiar surroundings.

Possible Solutions

In General

- Assess the environment. What are the potential hazards for the resident within his or her apartment? What can be made safer within the housing site and around the external environment if the resident regularly goes outside of the building?
- Focus on adapting rather than teaching. Avoid re-teaching the resident about safety issues. Instead, identify potential risks and take the appropriate precautions.

Self-care

- Encourage the resident to see a doctor for a complete checkup to rule out any medical conditions (e.g., medication reactions, infections) or sensory deficits (hearing or vision loss) that are creating an excess disability.
- Ask the doctor for an in-home evaluation by an occupational therapist to assess the home, identify problem areas, and recommend solutions.
- Home health nurses or family, if available, can set up pills for the resident. There are a wide variety of pill boxes available for this purpose, even ones that dispense medications at the proper times and give a verbal reminder to take them.
- Consider the need for help with handling finances. Direct deposit and automatic bill paying arrangements assure that the rent and other bills get paid on time. Contact your local area agency on aging. Some have volunteer programs to assist older people with bill paying and other paperwork.
- Eventually the resident will need someone else to take over the finances either through a power of attorney or a conservator legal arrangement. [See Chapter 8.]

In the home

- Use the checklist on the following page to assess the home for risks.

- A friend, family member or health professional working with the resident may be able to remove dangerous items and make simple modifications to the home to make it more dementia friendly for the resident. See the following checklist for suggestions.

Tips for Creating a Safe and Supportive Environment

Safety Checklist

Kitchen

- Lock up cleaning supplies
- Turn off electricity to garbage disposal
- Remove or hide knives and other dangerous utensils
- Consider automatic timers and shut-off devices for electrical appliances
- Shut off stove and arrange for home-delivered meals
- Clean out refrigerator regularly

Bathroom

- Set water temperature at 120 degrees
- Apply textured decals on slippery surfaces
- Supervise the use of electrical appliances
- Remove locks from the bathroom door
- Discard dangerous items from the medicine chest
- Install grab bars

Bedroom

- Avoid using electric blankets
- Install night lights between the bedroom and bathroom

Throughout the home

- Put away power tools, and limit access to large equipment such as lawnmowers and snowblowers
- Lock up poisonous products such as paints and fertilizers
- Remove all firearms
- Make sure that there is a working smoke detector and fire extinguisher
- Remove or tape down throw rugs and carpeting
- Apply colored decals to large windows and sliding glass doors
- Remove poisonous plants
- Create an even level of lighting near doorways, stairways and between rooms
- Remove objects that block walking paths
- Reduce clutter

Wandering

Wandering can be aimless or purposeful roaming that causes a resident to become lost, leave a safe environment, or intrude in inappropriate places. Either way, it is one of the most frequent and challenging problems that caregivers face. **Seventy percent of people with dementia will wander and become lost during the course of the disease, and most will do so repeatedly.** Someone with Alzheimer's may not only wander by foot but also by car or other mode of transportation.

- ✓ Help the resident to locate his or her apartment by inviting them to post their name on the door or display some other picture or object they will recognize.
 - ✓ Make sure that large-print floor numbers are prominently displayed at elevator entrances to help residents easily identify which floor is theirs.
 - ✓ Hold an educational program about memory loss and dementia for all residents. Provide information about what to do if they notice that one of their neighbors is missing or lost.
 - ✓ Hold a "Meet the Police" community policing event in the building. Encourage all residents to attend. Ask the police to offer free photo taking for emergency identification and notification cards to have on file at the police station and with the building manager.
 - ✓ Encourage the resident (or family, if available) to enroll the resident in Safe Return, a national, computerized data bank designed to identify, locate, and return to safety people who have wandered. Contact the Maine Alzheimer's Association Helpline at 1-800-660-2871 for information about scholarships for the one-time enrollment fee of \$40. [See Appendix for enrollment form and additional information].
- ➔ For more tips to prevent and/or respond to wandering see Appendix 4: *Wandering: Plan Ahead Because it Happens More Often Than You Think* (page xx).

Driving

People with early stage Alzheimer's disease may still be able to drive safely, but eventually they must stop driving. Alzheimer's disease impairs judgment, reaction time, and the ability to solve problems. It may also affect physical and sensory skills.

- ✓ Co-piloting is not recommended. Caregivers and neighbors, especially those dependent upon the resident with dementia for transportation, may attempt to keep the resident driving longer by giving directions and instructions on how to drive from the passenger seat. Warn them that this is dangerous because in hazardous situations there is simply not enough time for the driver with dementia to comprehend the warning and respond appropriately.¹
- ✓ Alert police when the resident drives away in a car and ask them to assess the resident's driving.
- ✓ If there is evidence that the resident is no longer safe to drive, report the resident the Division of Motor Vehicles for a driver evaluation.

- ✓ An occupational therapist can also evaluate driving capacity.
 - ✓ Ask the doctor to write a prescription instructing the resident not to drive.
 - ✓ Meanwhile assess the resident's need to drive and introduce him to alternate modes of transportation.
 - ✓ For residents determined to drive, with or without a license, it may be necessary to ask family members to take away the keys and remove the car.
- ➔ For an excellent discussion of this topic and additional tips, please see *At the Crossroads; A Guide to Alzheimer's Disease, Dementia & Driving*, which is included as an insert in this guidebook. For additional copies, contact The Hartford, 200 Executive Blvd., Southington, CT 06489, or visit their web site at www.thehartford.com/alzheimers

Sources

1. *Steps to Enhancing Your Home*, Alzheimer's Disease and Related Dementias Association, Inc., 1999.
2. *Steps to Ensuring Safety*, Alzheimer's Disease and Related Dementias Association, Inc., 1999.

Resources And Further Reading

- *The Do-Able Renewable Home: Making Your Home Fit Your Needs*, by John P.S. Salmen, American Association of Retired Persons, 2000.
 - *At the Crossroads: A Guide to Alzheimer's Disease, Dementia and Driving*, published by The Hartford, Southington, CT 2000.
 - *The Complete Guide to Alzheimer's-Proofing Your Home*, by Mark L. Warner, Purdue University Press, 1998.
 - *Homes that Help: Advice from Caregivers for Creating a Supportive Home*, by Richard V. Olson, Ph.D., et al., New Jersey Institute of Technology, 1993.
 - *The 36-Hour Day* (Third Edition), by Nancy L. Mace and Peter V. Rabins, The Johns Hopkins University Press, Baltimore, 1999.
- ➔ You can also order the following brochures by calling the Maine Alzheimer's Association at 1-800-660-2871.
- *Steps to Enhancing Your Home: Modifying the Environment*
 - *Steps to Ensuring Safety: Preventing Wandering and Getting Lost*
 - *Alzheimer's Association "Safe Return" Registration Brochure*

Appendix 5.1

Medication: Tips for Families and Direct Care Providers

As a caregiver you need to understand the use of medications, and be alert to possible over-medication and to adverse reactions to drug combinations. No medications prevent or cure Alzheimer's disease, but physicians rely on several drugs to manage delusions and hallucinations, as well as depression, agitation, or sleeplessness.

Although these medications may affect specific disease symptoms and assist in managing them, they can also produce side effects such as agitation, dry mouth, drowsiness, problems in walking, tremors, falling, or constipation.

Even though a physician might prescribe a drug for a limited period of time, it can sometimes take up to four weeks for a drug to leave the patient's system after use is discontinued.

Some medications can contribute to the Alzheimer patient's problems and make some symptoms even worse. For example, a resident who begins taking drugs for high blood pressure or a heart problem might appear to be more confused than before he or she began taking the drugs.

So-called anti-cholinergic drugs can also block the production of a chemical within the brain called acetylcholine and further alter the patient's memory.

To understand the effects of medications and how to manage their use, consider the following tips:

Action Steps

➔ Get medical advice

Be cautious about giving any medication — whether it's an over-the-counter or prescription variety. Begin by asking your physician to review all medications, in order to check for any possible interactions between drugs. Make sure that every physician involved in the resident's care knows about all prescribed medications.

Find out as much as possible about every medication, including its name, purpose, dosage, frequency, and possible side effects. If serious side effects occur, report them immediately to the resident's physician.

Continued

➔ **Be prudent**

Under no circumstances should you change the resident's dosages without first consulting his or her physician. In addition, avoid the temptation to exaggerate or over-report symptoms in order to persuade the physician to prescribe a new drug or to increase the resident's dosage. Do not share medications with other caregivers or keep medication bottles from old prescriptions.

➔ **Rely on your pharmacist for information**

Pharmacists can be an important source of information. Your local pharmacist can also check for interactions between drugs. Keep in mind that pharmacists can neither prescribe drugs nor alter drug dosages.

Maintain accurate and ongoing records. Keep a written record of all current medications, including the name of the medication, dosage, and starting date. The resident should carry a copy of this list in their wallet or purse at all times. This record will be invaluable in the event of a serious drug interaction or overdose.

➔ **Develop a routine**

Giving medications in a specific way at specific times of the day or evening will help to reduce conflicts. However, if the resident refuses to take the medication, stop and try again at a later time. Never assume that the resident will take medications on his or her own. It may be necessary to check to see whether the medicine has been swallowed. At some point in the progression of the disease, someone other than the resident will need to assume responsibility for giving medications.

➔ **Stay organized**

Helping the resident separate pills into a plastic container with small compartments labeled "day" and "evening" or "Monday," "Tuesday," "Wednesday," etc., will help in tracking medications. Some people find it useful to give medications in individual cups or envelopes, or to keep a calendar and check off each dose as it's taken.

Adapt to the resident. If the resident has problems swallowing pills or spits out the pills, you might try crushing pills and mixing them with applesauce or cottage cheese. Some medications may be available in liquid form.

➔ **Take safety precautions**

If necessary, put a lock on the medicine cabinet or place the medications in a locked drawer. If the resident spits out pills, make sure these pills aren't picked up and eaten by animals or anyone else. Avoid leaving the resident alone with medication bottles in the room. Be sure to throw out all old medicines.

Continued

➔ Be prepared for emergencies

Research the names and telephone numbers of pharmacies or taxi services that deliver medications. Also find out the names of pharmacies that are open on Sundays and weekends. Keep the number of your local poison control center or emergency room handy. If you suspect a medication overdose, call the number before inducing vomiting or taking any other action.

Appendix 5.2

Nutrition: **Tips for Families and Direct Care Providers**

Providing the Alzheimer patient with nutritious meals and snacks is a problem for many caregivers. Often the patient can't sense or identify hunger or fullness, or the need for fluids or foods with certain vitamins and minerals.

Predictability

The resident's response to food is also difficult to predict. An individual might like specific foods such as turkey or chicken and then—without warning—turn away from these foods.

Poor Nutrition

The result of poor nutrition among Alzheimer patients is usually weight loss or gain and a variety of other symptoms, including poor-fitting dentures, listlessness, and fatigue.

A resident who snacks regularly on such foods as candy and pastries often experiences a “sugar high” followed by complaints of being tired, depressed, or hungry. “Junk foods” tend to make the resident more restless and disoriented, and reduce the craving for regular meals and more nutritious foods. The resident may also experience bowel or bladder problems because of not drinking enough fluids or eating adequate fiber.

Disease Progression

As the disease progresses, providing the resident with proper nutrition may become even more difficult.

The individual might not understand the timing of meals or the difference between breakfast, lunch, dinner and snacks. In addition, you may have to offer more coaching at mealtime to help the resident use utensils, for chewing, swallowing, or identifying various foods. For example, you may hand the resident a spoon only to discover that he or she can't remember how to use it. In another situation, a resident who feels no need for food may clench their jaw tightly and refuse to let you put a utensil near their mouth. This resident may not understand or remember what to do with food.

ACTION STEPS

➡ Look for early behavior changes such as increased snacking, drastic shifts in food likes and dislikes, dramatic weight losses or gains, or bowel problems. Experiment with changes in the resident's diet to address these problems. You may need to allow for more time and offer more assistance at mealtime.

Continued

➔ **Monitor changes**

Check the resident's weight weekly and, on the advice of your doctor, have regular blood work completed, as needed. Laboratory reports will help to identify problems with cholesterol, anemia, dehydration, or constipation.

➔ **Prepare food for easier eating**

If the resident has problems with chewing, swallowing, or choking, try chopping or cutting the food into bite-size pieces.

➔ **Use food to trigger the patient's attention**

Use rough-textured foods such as toast or sandwiches made on toasted bread to stimulate the resident's tongue and encourage chewing and swallowing.

The resident with Alzheimer's sometimes has little sensation of food in the mouth. By gently moving the resident's chin, you can remind them to chew. Stimulate chewing by touching the resident's tongue with a fork or spoon. By lightly stroking their throat, you can remind them to swallow.

➔ **Use soft foods to assist the resident**

A resident who has problems chewing or who has poor-fitting dentures will benefit from foods of soft textures such as a peanut butter sandwich rather than a sandwich made of sliced meat, or a mashed potato rather than a fried potato.

You may want to serve mashed or steamed vegetables, bite-size pieces of cooked meat, or turkey or chicken salads instead of sliced meat. If swallowing becomes a problem, put food into a food processor or blender before serving it. Also remember that soups with two consistencies may confuse the individual.

➔ **Make knife-and-fork foods into finger foods**

If the resident's regular breakfast consists of scrambled eggs and bacon, cut the food into small squares. Or combine cheese, meat and eggs into an omelet so the resident can pick up the food with their fingers.

➔ **Proceed with caution in using liquid supplements**

Liquid food supplements are often costly, high in sodium, and can sometimes be prepared more economically at home. If the resident is eating regular meals, use supplements as an occasional between-meal or late-night snack or when the resident refuses to eat a regularly scheduled meal. When considering supplements, consult with your physician.

➔ **Work to make mealtime calm and comfortable**

Keep the environment quiet and free from such distractions as the television or radio. Try to maintain regular meals with the family for as long as possible. Social interaction and conversation are important. Feed the resident at regular intervals. Many caregivers find it helpful to serve several small meals rather than three large meals.

Continued

➔ **Be consistent**

Feed the resident in the same area at every meal and at the same approximate times each day.

➔ **Keep the table setting simple**

- Avoid placing objects on the table that might distract or confuse the individual.
- Put condiments on food before serving it to the resident.
- Set the table only with the utensils needed to eat the meal.
- Avoid using plates or placemats with patterns that might confuse the individual.
- Use a plate that's a different color from the placemat.
- Offer one food item at a time. A full plate with a meat, potato, and vegetable might overwhelm and confuse the resident.

Rely on nutritious finger foods as between-meal supplements

Encourage independence for as long as possible by allowing the resident to use utensils and eat finger foods. Holding a cup and drinking fluids through a straw will also give the resident a sense of accomplishment.

- Serve thick fluids to prevent choking. If choking occurs, be prepared to use the abdominal thrust to dislodge the food.
- Prepare the meal ahead of time so you can stay with the resident during the meal. He or she may mimic your eating behavior.
- Reduce between-meal snacks to ensure that the resident eats at regular meals, or provide the resident with fruit or nutritious snacks.

Appendix 5.3

Home Safety Checklist

Throughout the home . . .

- Place smoke detectors and fire extinguishers in hallways, at the top of stairwells, and in each room – especially the bedrooms.
- If the resident smokes, this activity must be supervised at all times.
- Lock-up or hide medications, and supervise the administration of all prescription and over-the-counter medicines.
- Place locks on doors and windows—high and low.
- Consider adding a bell or an electronic door alarm on outside door.
- Put away car keys.
- Apply colored decals to large windows and all sliding glass doors.
- Remove toxic plants.
- Remove or secure throw rugs.
- Order a safe return ID bracelet if wandering is a concern.
- Lock up poisonous or dangerous products, including cleaning supplies and tools.
- Hide or remove firearms, knives or other weapons.

In the bathroom . . .

- Adjust the water temp to 120° degrees or less.
- Install a hand-held shower and grab-bars in the tub.
- Add a tub chair with a back.
- Apply non-skid safety strips or a bath mat in tub or shower.

Continued

- Install a raised toilet seat and a grab bar if mobility is a problem.
- Remove bathroom door lock
- Discard dangerous items in the medicine chest
- Make sure there are nightlights along the route from the bedroom to the bathroom.

In the kitchen . . .

- Remove stove knobs or turn off circuit breaker, or hook up stove to a hidden gas valve or electric switch. Pay special attention to this if the resident is left alone for a while. Watch for burned-on or missing pots, pans, or teakettles.
- Clean out refrigerator of spoiled food
- Try auto shut-off appliances

Appendix 5.4

Wandering: Plan Ahead Because It Happens More Often Than You Think

Wandering is defined as either aimless or purposeful roaming that causes problems such as getting lost, leaving a safe environment, or intruding in inappropriate places. At least 70% of people with dementia will wander at some point during the course of their disease, and most will do so repeatedly. Someone with Alzheimer's may not only wander by foot but also by car or some other mode of transportation. They may end up hundreds of miles from home. People with Alzheimer's disease typically do not behave like most lost adults: they do not recognize that they are lost, they leave few physical clues, and they are unlikely to call out for help or respond to shouts from searchers. A missing resident with Alzheimer's disease is always an emergency situation because he or she is at risk for serious injury and possibly death. In fact, 46% of those not located within 24 hours of the time last seen die, usually succumbing to hypothermia and/or dehydration.

It is difficult to predict when a resident with Alzheimer's disease will begin wandering. However, wandering incidents are prevalent in Maine as evidenced by the experiences of the more than 600 law enforcement officials, emergency medical crews, mall security staff, K-9 search and rescue volunteers, and officers of the Maine Warden Service trained by the Alzheimer's Association over the past two years. Participants related numerous incidents including:

- a woman who wandered into a neighbor's attic
- a woman who was lost for five days in a remote wooded tract
- a man in a cotton bathrobe found walking alone on a January night
- a woman missing from a care facility found sleeping under someone else's bed
- a man on foot in the middle of one of Portland's busiest streets, acting as if he were driving a car
- a man who started out in New Hampshire and was found driving the wrong way down a one-way street in Auburn, Maine, looking for his daughter's home.

Most of these stories had happy endings. Some, sadly, did not.

➡ **The best advice is to assume that the resident with Alzheimer's or dementia will wander at some point and plan accordingly.** To help you do this we have compiled some tips for understanding and preventing wandering behavior. We have also asked the Maine Warden Service for advice on what caregivers can do to prepare for and respond

to a wandering incident because collectively their 120 officers have vast experience searching for people with Alzheimer's disease. The Maine Wardens Service originated in

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1880 as a law enforcement branch of the Department of Inland Fisheries and Wildlife to protect inland fish and wildlife resources. Over the years, their mission expanded to include primary responsibility for the search and rescue of lost persons in all but the most urban areas of the state. They will also search in city environs if the possibility exists that weather conditions will endanger the victim. Wardens frequently work in cooperation with local law enforcement and rescue groups.

Understanding Wandering

Wandering may be triggered when a resident with Alzheimer's:

- No longer recognizes familiar people, places, and objects
- Feels lost in a new or changed environment
- Tries to fulfill former obligations, such as going to work or taking care of a child
- Takes medications that have side effects such as restlessness and confusion
- Tries to relieve stress caused by noise, crowds, or isolation
- Experiences confusion at certain times of the day or night
- Is restless due to lack of physical activity
- Is fearful of unfamiliar sights, sounds, or hallucinations
- Searches for something specific such as food, drink, the bathroom, or companionship
- Looks for a way out of the home.

Tips To Prevent Wandering

- Prevent unsafe exits from the house or backyard by placing door and window locks out of sight and reach, either very high or very low. Use a double-bolt lock, and keep the key handy in case there is an emergency.
- Consider high-tech devices, such as electronic buzzers or bells to signal when a door is opened, or a pressure-sensitive mat at the door or resident's bedside that sounds an alarm to alert you to movement.
- Try camouflaging doors by papering or painting them to match the walls, or labeling them in such a way as to be undesirable to the resident (e.g., to discourage a woman from entering, label the door "Men's Locker Room").
- Check to see if the resident is hungry, needs to go to the bathroom, or feels uncomfortable.
- Encourage movement and exercise to reduce anxiety and restlessness.
- Involve the resident in daily activities such as folding laundry or preparing a meal.
- Remind the resident that you know how to find him and that he or she is in the right place.
- Reduce noise levels and confusion.
- Observe if wandering behavior occurs at a regular time each day and try to find a cause. Try to distract the resident to another activity during that time.

- If night wandering is a problem, try restricting fluids in the evening and make sure that the resident uses the bathroom before going to bed. If possible, limit naps during the day.

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Where To Call For Help

➡ **Register the resident in the Safe Return program** sponsored by the Alzheimer's Association. This will help to provide information and identification if authorities find your loved one. Call **1-800-660-2871** for a registration form. There is a one-time enrollment fee of \$40; scholarships are available from the Maine Alzheimer's Association.

➡ For additional tips or ones specific to your situation, call the Alzheimer's Association HELPLINE at **1-800-660-2871**.

Advice From the Search and Rescue Experts

There are a number of things that caregivers can do to help law enforcement and search and rescue personnel find missing persons. We are grateful to Training Supervisor, Mark Warren, and Game Warden Specialist, Deborah Palman, from the Maine Warden Service for the following insights:

➡ **Plan Ahead**

1. Before you need their help, introduce yourself and the resident to the local law enforcement officers, game wardens, fire chief, and search and rescue group leader if such a group exists near your town. This will help them to recognize the resident and keep special watch if they see him or her in their travels, and help your loved one to understand that these people may be trying to help him or her find their way home.

2. Talk to neighbors about the resident's condition. Give them names and numbers of whom to call if they see the resident outdoors without supervision. Ask them to pay special attention to the time and place they saw the resident.

3. Keep a log of the resident's behavior patterns, especially places they like to walk or travel. Encourage them to tell you where they are going if they go out alone. Often people become lost when they make a small deviation from their usual route. Knowing the route gives searchers a place to start from. Rick Davis, Chief of the York County Emergency Rescue Team, also encourages caregivers to make note of what the resident liked to do in the past, since they may be trying to re-enact those earlier memories. One woman, for instance, walked 8 miles, bushwhacking her way through an overgrown mountain trail because that had been her favorite place to play as a child. Other important information

from the resident's past includes former neighborhoods, places of worship, workplaces or favorite places to spend time. In addition to the above information, the search and rescue leader will also ask you the specific time and place your loved one was last seen,

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information about any previous wandering incidents, and what the resident was doing and talking about just prior to his or her disappearance.

- 4. Note what the resident is wearing each day.** An accurate description of what the resident is wearing is essential during a search.
- 5. Provide brightly colored clothing for the resident to wear.** Bright colors are much easier to spot in thick vegetation or from an airplane and help motorists to see the wearer.
- 6. Make rubbings, prints or drawings of the soles of the footwear the resident wears.** Footprints are vital clues for search and rescue personnel, and having an exact duplicate of the footwear pattern is very valuable information. Try to keep track of what they are wearing for footwear, or be able to determine what they are wearing by what is missing.
- 7. Keep an updated list of the resident's identifying information:** height, weight, hair color, blood type, eye color, identifying marks, medical condition, dental work, jewelry, allergies, and complexion.
- 8. Make multiple copies of a recent photograph.**
- 9. Keep scented clothing on hand** in the event that rescue dogs are involved in the search. Wearing plastic gloves or using tongs or pliers, store a piece of the resident's unwashed clothing in a bag where it will not be disturbed. Replace it monthly to retain the scent. It is critical that the article contains only the scent of the lost person. For this reason, be sure that you do not touch the item directly, and avoid taking clothing from the family clothes hamper or from areas that every one uses.
- 11. Identify dangerous areas near the home,** such as bodies of water, swimming pools, dense foliage, tunnels, bus stops, steep stairways, high balconies, and heavy traffic roadways. Check these places first if someone becomes lost.
- 12. Keep a list of emergency phone numbers.** In Maine, this list should include the local law enforcement agency; the emergency number of local Maine State Police Office, which can contact the Maine Warden Service (the agency in charge of search and rescue in the woods and waters); and telephone numbers of relatives, friends and/or neighbors who live nearby who can assist in the search if the resident becomes lost.

➡ If The Resident Is Missing

1. Call your local law enforcement agency. DO THIS FIRST! The biggest single problem hampering a search is the delay in calling for help. Let the dispatcher know that a person with dementia may be missing and that you are going to conduct a search of the premises. You can always call back if the resident is found right away. If not, professional helpers have already been alerted and are getting ready to respond.

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2. Call friends, relatives or neighbors to come help you. Someone will need to stay near the phone while others search. Often a caregiver panics or becomes distraught and doesn't search areas well. The search and rescue rule for small children is: "Search the house, search the house, search the house again," because small children often hide in places their parents never think of. The same is true of a person with dementia because they often panic and hide in unlikely places such as closets or small crawlways. Search the property and buildings and have nearby neighbors check their houses and yards. Be aware that professional searchers will go over these locations again when they arrive on the scene just to be sure that nothing has been overlooked.

3. If the resident is not found within a short time, call your local law enforcement agency again. Be sure to stress that the resident has Alzheimer's and may not be able to help him- or herself if they are lost. The resident may become endangered if not found soon. This is especially crucial if the weather is bad. Ask the agency to contact a K-9 (dog) team to help. Many law enforcement agencies have their own K-9 teams, or trained teams are available from the Maine State Police, Maine Warden Service, and Maine Search and Rescue Dogs, which can be contacted through the Maine Warden Service.

4. Notify the Maine Warden Service. If your local law enforcement agency does not contact them, contact the Warden Service yourself through the nearest State Police office. If it still seems like no one will be responding, keep trying.

5. Make sure someone stays near the phone once an emergency response agency has been called. Because those who answer the phone during the search will need to answer questions about the lost resident, it should be someone who is familiar with the resident's dress and habits. If the Resident Coordinator is designated as the best person to stay near the phone, get help from others to search the local area and perform other tasks. Use a cell phone or another phone line so that the number you gave to emergency personnel remains free for incoming calls.

6. Tell local searchers to be alert for clues like footprints and litter. Often, these clues are destroyed by people who are unaware that they are destroying the signs that can be used to help find the lost resident. Unless those searching are trained woodsmen who can recognize the sign of the lost resident, it is best if the family or friends stay out of the woods and check local buildings, yards and other areas the lost resident may be. Trained search and rescue personnel who can read signs and track the person in the woods or in the dirt beside the road will be responding. Keeping people out of uninhabited areas also makes it easier for dog teams to search these areas. Keep in mind that the lost person may also be moving and move into areas that have already been searched.

7. Have someone ride the local roads to watch for the lost resident who may find his or her way to a road. Make sure these persons look for footprints if they are driving on dirt roads, and have them preserve any footprints they find which might belong to the lost person.

Continued

8. Don't clean up the house or the lost resident's room. A K-9 handler will want to obtain a scented article that has only the resident's scent on it. The handler or another trained person should be the one to retrieve the article. Often a pillowcase from an unmade bed is best. Investigators will also want to look around for clues that may tell where the person went.

9. Stay calm. Most lost persons are found unharmed within a few hours of being missing. Lost persons, even those with dementia, have surprising resilience when lost.

Emergency Phone Numbers

Maine State Police:	Augusta	1-800-452-4664
	Houlton	1-800-924-2261
	Orono	1-800-432-7381
	Scarborough	1-800-482-0730

Local search and rescue groups: call the Dept. of Inland Fisheries and Wildlife Safety Office at 207-287-5222 (Business Hours Only).

Maine Search and Rescue Dogs: call the pager number at 207-471-DOGS (207-471-3647).

Appendix 5.5

On the following page is a registration brochure from the Alzheimer's Association **Safe Return** program. To order additional copies, call the Maine Alzheimer's Association toll-free at 1-800-660-2871.

Appendix 5.6

On the following pages we have provided a photocopy of the **Driver Medical Evaluation** form from the Maine Secretary of State, Department of Motor Vehicles. This form should be provided to the resident's physician if you become concerned that he or she may not be able to safely operate a vehicle.

Appendix 5.7

Sample Letter To Report An Unsafe Driver

On the following page we have provided a sample letter you may wish to use if you feel that a resident with Alzheimer's or dementia can no longer safely operate a vehicle. Of course, in addition to filing this letter with the Secretary of State, you should also notify the resident's family or caregivers of any driving-related mishaps or accidents involving the resident. For more information, you can also call the Medical Review Coordinator for the Bureau of Motor Vehicles at (207) 624-9000, ext. 52125.

SAMPLE LETTER

Secretary of State
Medical Records Review
State House Station 29
Augusta, ME 04335

Re: Mr/Mrs. John Doe
Name of Residential Facility
Address
City, State Zip code

Dear Sir or Madam:

This letter is a formal request for a medical review of the driver's license of [name of resident] whose date of birth is [month/date/year].

As the [Resident Coordinator/other title] at [insert name of residential facility], I have become concerned about the ability of one of our residents, [Name of resident], to safely operate a motor vehicle. Recently, [Mr./Mrs./Ms. Name of resident] has been involved in several mishaps while driving [his/her] car. [You may wish to describe an incident here.]

Although no summons was issued in any of these incidents, I have told [Mr./Mrs./Ms. Name of resident] that I would be contacting your office. I [know/believe] that [Mr./Mrs./Ms. Name of resident] [is/may be] suffering from a form of cognitive impairment associated with Alzheimer's disease or a related dementia that makes it increasingly difficult for [him/her] to drive safely.

According to our records, this resident's primary physician is:

Name of Doctor
Name of Hospital or Practice
Address
City, State and Zip Code
Phone number

Thank you for your review of this matter.

Sincerely,

Your name
Title

Chapter 6

Strategies for Handling the Situation

There are many services available to assist people with Alzheimer's, as well as services for their families and caregivers. It's important to identify resources available in your community, and to understand your role and responsibilities in the coordination of these services.

Dementia In Housing

Within the Housing industry, there are a number of housing professionals who will, at some point, come into direct contact with residents. These may include, but are not limited to, the following:

- Property Managers
- Site Managers
- Maintenance Technicians
- Housekeeping

When a member of the housing team encounters an individual that he or she suspects may have dementia, a referral should be made to the Resident Service Coordinator. If there is no Resident Service Coordinator on staff, housing professionals should discuss concerns with members of the resident's family or the emergency contact listed in resident's file. Concerns should be communicated in terms of specific behaviors. When no family members are available, housing staff should consult with an outside agency such as the Maine Alzheimer's Association. For a complete list of agencies please see Chapter 10.

The Role Of The Resident Service Coordinator

Service Coordination is a resident-driven program designed to assist residents to live safely and independently. The RSC's primary role is to link residents with services in the community, advocate when necessary, and provide education about area services and benefit programs.

Alzheimer's and Memory Impaired residents are a special concern for the RSC in housing as the signs and symptoms are sometimes overlooked or misinterpreted. Recognizing warning signs is crucial in identifying that there may be a problem and beginning the process of assisting residents in getting the help they need. Therefore, a

crucial part of being an effective Resident Service Coordinator is to seek educational opportunities around Alzheimer's disease as well as other diseases that may affect the lives of residents.

Confidentiality. Resident Service Coordinators are bound by codes of confidentiality. That is, they are not permitted to reveal any information received on a confidential basis to anyone not authorized in writing by the resident. The only permissible exceptions to this rule are:

- If a resident is a danger to himself or herself or others
- If a RSC is subpoenaed in a court of law
- If the resident is engaging in lease violating behavior (most, but not all, projects require the RSC to report lease violations).

Release of information. Resident Service Coordinators do attempt to obtain a release form from each resident when the resident first moves in to the site and then again at annual re-certification. If, over the course of a RSC's work with a resident, the situation warrants, the RSC may again request that the resident sign a release of information. Residents are not required to sign a release form. A resident may revoke a release at any time, or opt to sign a release at any time should it become evident that he/she may require assistance in obtaining services, information or assistance from an outside person/agency.

Providing education. Whenever possible, RSCs meet with residents, residents' family members, members of the community and housing staff to provide materials and information about Alzheimer's Disease and other related dementias. Often times efforts to educate residents demands creativity and sensitivity.

Support. Whenever possible, make an attempt to involve a resident's family, friends, and caregivers in the educational process. These people provide the resident with a crucial support system, as well as a mouthpiece to communicate important information to helping professionals.

Tips for approaching the resident

- Follow up any written communication with a face-to-face visit.
- Follow up any face-to-face visit with a written communication summarizing the discussion. (Always keep a copy of any written correspondence and notes in the resident file.)
- However, recognize that the resident may no longer be able to comprehend written notices and warnings and therefore may fail to comply with the instructions they contain.
- Choose the resident's best time of day for an important meeting.
- Consider holding the meeting in the resident's apartment where he or she is most likely to be relaxed and oriented.
- Remember: Your approach is critical because the resident will likely mirror your tone. Be calm, reassuring and supportive. [See Chapter 3 for more tips.]

- Remember that the resident is not being deliberately stubborn, defiant or non-compliant, nor are they being manipulative – they have a disease.
- Avoid long explanations, legalese and jargon.
- If the resident seems frustrated or upset, back off. Reassure him or her that you are there to help. Change the subject to a pleasant topic and try again later.

Handling Specific Situations: Factors to Consider

How to handle a specific situation depends on whether or not it is an emergency and whether or not there is a current release of information on file authorizing you to obtain or share information on the resident’s behalf. The following flowcharts and scenarios are intended to assist you in determining the best course of action.

Emergency Scenario

Example: Emergency With No Release of Information

An 83-year-old female was living in senior housing. Neighbors reported to the site manager that the woman seemed very different. She was wandering the hallway late at night, looked disheveled, and was non-communicative. A referral was made to the RSC, who scheduled a visit to the woman’s apartment. When the RSC entered, the kitchen and hallway floors were covered with bottles of cleaning products. The woman was unkempt and the apartment was cluttered. The RSC asked the woman what she was doing with the cleaning products spread out on the floor. The woman responded that she was going to kill herself. When the RSC asked her how she was going to kill herself, the resident responded that she was going to “drink bleach.”

➔ Response to Emergency Scenario

In any emergency, it is critical to contact the appropriate crisis service immediately. The crisis services available, depending on the situation, include the police, the fire department, crisis stabilization, emergency rescue, etc. If you believe that the appropriate course of action is calling the police, you may request that they bring a mental health crisis team with them.

After contacting the appropriate agency, document as accurately as possible your observations. In a housing situation, the property manager should be notified as soon as possible.

After the resident has met with the crisis service, the emergency contact listed in the resident’s file should be notified, along with family members. During your phone conversation with the family member and/or the emergency contact, share your concerns, the list of your documented

observations, and how the behavior or situation might affect the resident's housing status.

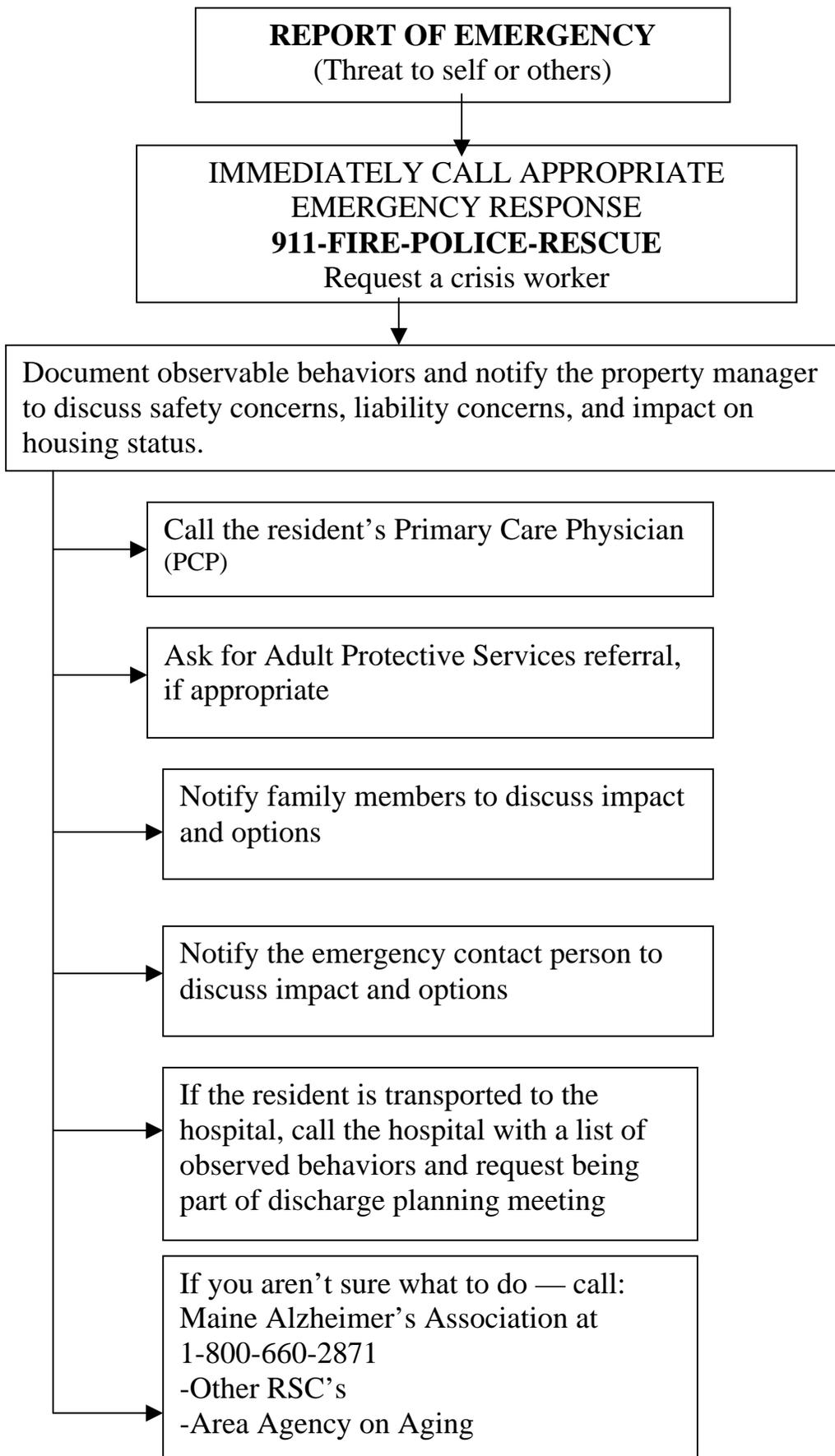
The immediate safety of the resident, staff, and community is paramount. If the resident's behavior is "dangerous," the police have the authority to transport the resident to the emergency room for evaluation by a qualified medical professional.

If the behavior is ongoing and significant, and the family, emergency contact, and crisis services are of limited assistance, a referral to the Department of Human Services/Adult Protective Services may be necessary.

If the resident is transported to the hospital, call the emergency room of the hospital and give them the list of the documented, observable behaviors and your concerns. Additionally, request that if the resident is admitted to the hospital you would like to be invited to any discharge planning meeting prior to the resident's release.

Your discussion with the emergency contact and family members might include an overture to assist with exploring alternative housing options. It is also important to review with the family the impact of the behavior on the resident's housing status, your safety concerns, and what steps might be taken next.

On the following page is a flowchart showing the appropriate sequence of responses to an emergency situation with no release of information.



Non-Emergency Scenario

Example: Non-Emergency Scenario with No Release of Information

An elderly resident begins wandering into closets off the community room, mistaking them for apartment doors. He also begins seeking food in the community room refrigerator, mistaking it for his own. He reported being hungry and was unable to remember when he last ate. Other residents observed him picking up small objects in their apartments and pocketing them as his own. He started smoking in the hallways, although he had always been aware that this behavior was a violation of house rules.

➔ Response to Non-Emergency Situation

In many instances, housing professionals may observe resident behavior that is not threatening or dangerous, but is cause for concern. Some examples are:

- ➔ Changes in appearance or behavior
- ➔ Agitation
- ➔ Confusion
- ➔ Change in the condition of apartment or living quarters.

The RSC's response is largely dependent on whether or not they have obtained a signed Release of Information as the following scenario illustrates:

On the following pages are two flowcharts showing the appropriate sequence of responses to a non-emergency situation where there is no release of information.

**NON-EMERGENCY WITH NO
RELEASE OF INFORMATION**

Observe and document the resident's behavior

Notify the property manager if you are concerned about a lease violation or liability

If the behavior violates the resident's lease, the property manager will send a lease violation letter, including a referral, to the RSC

RSC Response

- Meet with the resident and ask them to sign the Release of Information
- Contact Alzheimer's Association for information
- Document any changes in the resident and any referrals to outside agencies
- Provide general education to residents, family, and staff

**NON-EMERGENCY REPORT OF INCIDENT
WITH A RELEASE OF INFORMATION**

Resident Services
Coordination Referral

Schedule a home visit with the resident. During your visit, be sure to:

- Update the Release of Information, including health care providers and caregivers
- Observe and document the resident's behaviors and appearance, as well as the condition of the unit
- Discuss with the resident the need to schedule a visit to the primary care physician

Yes, the resident will see
his or her PCP

No, the resident will not
see his or her PCP

Help resident schedule a
visit with his or her Primary
Care Physician, and be sure
to discuss transportation.

Ask the resident if they
would be comfortable
with a nurse coming to
see them

Other possible actions:

- Contact Homemaking services
- Contact Family Emergency contact
- Contact Adult Protective Services (when appropriate)

Send a fax to the Primary
Care Physician's office
describing all observable
behaviors and concerns

Yes, they will see a nurse,

- ➔ Call the PCP for a fax referral to a home health agency for a psych nurse to go into the home or apartment
- ➔ Contact the home health agency that the fax referral is being sent and share all observable behaviors and concerns with them
- ➔ Facilitate entrance to the building, if necessary.

Dealing with Neighbors

In senior housing projects neighbors often take on the role of family caregivers for each other. Sometimes the helping relationship is a mutual give and take. Other times a resident's need for assistance is easily accommodated (for example, a reminder of upcoming events or running an errand or two). Over time the need for assistance, especially if the resident has dementia, may escalate to the point where the helpful neighbor feels overextended and overwhelmed. He or she may feel unable to set limits with the needy resident and reluctant to report the situation to management for fear of getting the resident kicked out. When this happens, neighbors run the same risk of caregiver stress and burnout as family caregivers do.

Caregiver Stress

More than 80 percent of Alzheimer caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression. Many caregivers don't recognize their needs, fail to do anything about them, or simply don't know where to turn for help. Too much stress can be damaging to caregivers. Recognizing the signs and learning how to reduce stress can help.

➔ Warning signs of caregiver stress

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

➔ Tips for reducing caregiver stress

- Educate neighbors about dementia and caregiver stress via flyers and small information sessions with invited guest speakers from the Alzheimer's Association, local support groups and other appropriate community organizations.
- Provide information to all residents about the RSCs role and how he/she can help if they are concerned about the well being of a neighbor and/or their own role as a helper to this resident.
- Be alert to the signs of caregiver stress in situations where you know that someone has taken on a caregiver role for a neighbor.
- Encourage neighbors to call the Alzheimer's Association Helpline (1-800-660-2871) for specific coping strategies as well as a safe place to express their feelings and concerns.
- Encourage neighbors to be realistic and firm about what they can and cannot do.

- Involve family (if available) and community providers so that the neighbor can reduce his/her involvement without feeling guilty about abandoning a resident in need. Get help from family, friends, and community resources
- Encourage neighbors to take care of their own health needs.
- Give neighbors credit for what they have done up to this point. Don't do or say anything to make them feel guilty about needing to step back now. Give them explicit encouragement and permission to take care of themselves.

Dealing With Family

Families provide the majority of care (75%) to their loved ones with Alzheimer's disease and related dementias. The financial, emotional and physical drain on their resources is incalculable. They are truly the hidden victims and unsung heroes of this disease. However, residents of senior housing may be without family support either because the family is non-existent or uninvolved.

➔ Tips for Involving Families

- Encourage the resident to sign a release of information allowing you to talk with the family (a release is not necessary in an emergency or lease-violating situation)
- Notify the family of your concerns citing specific situations and behaviors.
- Encourage the family to be involved in the diagnostic process for their relative.
- Encourage the family to call the Maine Alzheimer's Association for information and support.

Resources And Further Reading

1. *Service Coordination and Consumer-Driven Services in Senior Housing*, published by the Maine State Housing Authority in June of 1996. For more information about this publication, please contact the Maine State Housing Authority at 1-800-452-4668.
2. *York-Cumberland Housing Resident Service Coordination Policies and Procedures*, Revised Edition, January 2000. For more information about this publication, please contact Susan Gay at 1-800-339-6516.
3. *Woodcock Management's Supportive Services Policies and Procedures Manual*, for more information, please contact Mary Weiss, Director of Supportive Services at (207)774-0501.
4. *A Handbook on the Legal Obligations and Rights of Public and Assisted-Housing: Providers under Federal and State Fair Housing Law for Applicants and Tenants with Disabilities*, by Debbie Pitch, J.D., Pitch Associates, Inc. in consultation with Ann Anderson, M.M.H.S., Massachusetts Housing Finance Agency, and Patricia M. Ender, J.D., Pine Tree Legal Assistance, Inc. Revised April 1995. This publication was produced under the Department of Housing and Urban Development's Fair Housing Initiative program Grant.
5. *Fair Housing: Guidebook for Owners and Managers of Apartments*, sponsored by the National Affordable Housing Management Association. For more information, or to order copies of the guidebook, call 877-563-4605.

Appendix 6.1

Sample: Release of Information

I hereby authorize the release of information to be used by the Service Coordinator at _____ to link me with programs and services that will assist me in remaining independent and self-sufficient.

_____ is authorized to receive information pertaining to benefits or services provided to me. [He/She] is authorized to provide information to the following service providers in order to access or maintain the services I desire. This authorization will remain in effect for one year, and expires on _____.

- | | |
|---|---|
| <input type="checkbox"/> Area Agency on Aging | <input type="checkbox"/> Family Members |
| <input type="checkbox"/> Home Health Agencies | <input type="checkbox"/> Mental Health Agencies |
| <input type="checkbox"/> Substance Abuse Agencies | <input type="checkbox"/> Department of Human Services |
| <input type="checkbox"/> Social Security Administration | <input type="checkbox"/> Veterans' Administration |
| <input type="checkbox"/> Physician _____ | |
| <input type="checkbox"/> Physician _____ | |
| <input type="checkbox"/> Other _____ | |

I understand that the use of this information is strictly confidential, and that it may only be shared with those agencies and/or individuals involved in the delivery of services I desire, and with state or federal agencies who may need this information to monitor the quality of services provided to me. I also understand that I have the right to revoke this consent at any time.

Name: _____ Date: _____

Signature: _____

I, _____, revoke this authorization of confidential information.

Signature: _____ Date: _____

Source: Bureau of Elder and Adult Services, Portland, Maine.

Appendix 6.2

Sample: Incident Report

Site Name: _____ Date: _____

Resident Name: _____ Apt: _____

Incident Report By: _____

Staff (title): _____ Other: _____

Date of Incident: _____ Time: _____ a.m./p.m.

Description of Incident _____

Who was notified about this incident?

Management Office Physician

Police Family

Fire Other: _____

EMS Other: _____

Witness Information

Name: _____ Phone: _____

Name: _____ Phone: _____

Staff response to incident: _____

Follow-up action: _____

Letter to resident Date: _____

Conference with resident Date: _____

Agency contacted: _____ Date: _____

Prepared by: _____ Date: _____

Source: Mary Fowler, Property Manager, Woodcock Management, Inc., Portland, Maine.

Appendix 6.3

Lease Violation Letters

Below and on the following page you will find two sample **Lease Violation** letters you may wish to use in the event of you need to notify a resident that he or she is in violation of the facility's lease agreement. You should amend the letters, where appropriate, to reflect the particular circumstances at hand. If possible, print the letter in a type size (14 point minimum) that will be easy for an elderly resident to read.

If you have an RSC on your staff, you may want to insert a referral to the RSC in your standard lease violation letter and forward a copy to your RSC.

<p>[Date]</p> <p>[Mr./Mrs./Ms. Resident's Name Street Address and Apartment # City, State and Zip Code]</p> <p>Dear Mr./Mrs./Ms./ [Name],</p> <p>[A brief description of the lease-violating behavior.]</p> <p>[Explicit citation of the section of the lease that is being violated.]</p> <p>Referral to RSC. A referral has been made to Jane Doe, the Resident Service Coordinator. She will be contacting you to discuss any services or information you may need.</p> <p>Sincerely,</p> <p>Name Property Manager [Name of housing facility]</p> <p>cc: name of RSC</p>
--

➔ **Important.** Consider softening your standard lease-violation letter. Please be aware that an abrupt, cold, and threatening letter will be less effective with a person with dementia than one that is simple, uncluttered with “legalese,” and expresses genuine concern for the resident's well being. An excellent example of this type of letter, excerpted below, is provided by Mark Alper, Director, Fair Housing Compliance, National Center for Housing Management, in his article “How To Get Help For Elderly

Residents Who Violate The Lease,” (Brownstone, 1999.) The entire article is reprinted with permission in Appendix 5.

Model Letter

Here’s an example of a letter to send to an elderly resident who’s having trouble coping and who has violated her lease. The letter points out the problem the resident is causing – in this case leaving the bathroom faucets on. It informs the resident that she’s endangering herself and violating the lease. And it tells her than you’d like to discuss the situation with her.

Dear Jane Resident:

It has come to our attention that you have repeatedly left your bathroom faucets running and flooded your bathroom. The residents in the apartment below you have observed water leaking from their ceiling. A member of our maintenance staff investigated and determined that the water came from your apartment when you left the faucet on.

Leaving the water running creates a danger to you and to other residents. You could slip on the wet floor. The residents below might be injured by a falling ceiling. These repeated incidents violate your lease. We would like to speak to you about the situation. Please give us a call or come into our office so we can discuss how we can help you. We will call you in a few days if we do not hear from you.

Yours truly,
John Manager

Tips For Writing An Effective Lease-Violation Letter

- Make the letter easy for the resident to read.
- Use large-print (14 point) type. Use large print on the envelope, too.
- Use the least amount of “legalese” possible, and no jargon or acronyms.
- Use short sentences with uncomplicated words.
- Periodically, insert the resident’s name into the body of the letter so that he or she knows that the content of the letter is addressed to them.
- Use a direct but warm tone.
- Think about your own parents reading this letter.

Appendix 6.4

Service Coordinator Referral

Date: _____

Name of Resident: _____

Name of Property: _____

Apartment: _____ Phone Number: _____

Social Security Number: _____ Income: _____

Referred by: _____ Title: _____

Reason for the Referral (check all that apply)

Move-in Other: _____

Services Other: _____

Lease Violation Other: _____

Brief Description

RSC Response (RSC will complete below this line)

Date: _____ (Codes _____)

Action Taken:

Follow-up Required? Yes No

If Yes, follow-up action is required by: Property Manager RSC Other

Follow-up Action:

Source: Maine State Housing Authority.

Appendix 6.5

How To Get Help For Elderly Residents Who Violate The Lease

Reprinted with permission from the Site Manager's Complete Guide to Assisted Housing (1999). Copyright, Brownstone Publishers, Inc., 149 Fifth Ave., New York, N.Y. 10010-6810. For a free sample issue, call 1-800-643-8095.

What do you do when an elderly resident's inability to care for himself result in lease violations? Many assisted sites have elderly residents in this situation. Ill health, senility, poor eyesight or hearing – all the ravages of age – have acted against these residents. They've stopped cleaning, let bathtubs overflow, forgotten to pay rent, or left burners on.

Eviction isn't a desirable answer. In fact, many of these residents may have been model residents for years. But if you don't take preventative steps, the consequences could be disastrous, not only for the residents and your building but also for other residents who can hold you responsible.

You're in a difficult situation. "Housing professionals aren't social service workers or doctors," says Mark Alper, director of fair housing compliance at the National Center for Housing Management and a former property manager. Most aren't trained to deal with elderly resident in trouble. But they face the problem more frequently as the population ages and more elderly live on their own.

To address the problem before it becomes an emergency, consider following our three-step procedure. These steps have worked for top property managers who've used them at their sites. They'll also help you avoid fair housing lawsuits, says Alper (see box below).

Step #1: Contact Resident

Start by writing a letter to the resident detailing the lease violations. While you don't want to threaten an 80-year-old with eviction, you want the resident to understand the seriousness of the situation, says Alper. You also want to offer your help. Ask the resident to come and talk to you about the situation. We've put together a Model Letter to help you do this (see Model Letter that follows). Our letter explains to the resident that she's caused a problem at the site and asks her to contact management to discuss it.

Continued

If you don't hear from the resident in a few days, follow-up your letter with a phone call asking the resident to come in to speak to you. When you meet with the resident, tell her you're concerned about her well-being. Ask her to please be more careful and the mention the lease violations. Ask if she needs help. The resident may say she's fine and needs no help. But if she admits she needs help, ask what she needs.

Model Letter

Send Letter to Elderly Resident to Discuss Lease Violations

Here's an example of a letter to send to an elderly resident who's having trouble coping and who has violated her lease. The letter points out the problem the resident is causing – in this case leaving the bathroom faucets on. It informs the resident that she's endangering herself and violating the lease. And it tells her than you'd like to discuss the situation with her.

Dear Jane Resident:

It has come to our attention that you have repeatedly left your bathroom faucets running and flooded your bathroom. The residents in the apartment below you have observed water leaking from their ceiling. A member of our maintenance staff investigated and determined that the water came from your apartment when you left the faucet on.

Leaving the water running creates a danger to you and to other residents. You could slip on the wet floor. The residents below might be injured by a falling ceiling. These repeated incidents violate your lease. We would like to speak to you about the situation. Please give us a call or come into our office so we can discuss how we can help you. We will call you in a few days if we do not hear from you.

Yours truly,
John Manager

Step #2: Call Family Members

If the situation doesn't improve, or if the resident asks for help, call family members. (You may have their names in the resident's files.) This strategy worked at one property Alper managed. An elderly resident was extremely anxious, and her mental condition appeared to be deteriorating. She would awaken in a panic in the middle of the night and pull the fire alarm. The fire department had to send trucks to the apartment community 15 to 20 times a month. Obviously, the resident was creating a nuisance, and other residents were upset.

Continued

The property manager spoke to the resident and wrote to her expressing concern. The false alarms continued, and the property manager called the resident's son to arrange a meeting. When the son, the community's staff, and the resident met, the resident explained that she hadn't wanted to bother her son when she felt panicked because she knew he was very busy. Her son told her to call him whenever she felt panicked rather than pull the fire alarm. The false alarms ceased, and the resident was able to continue living in her apartment.

Step #3: Contact Services for Elderly Residents

If contacting family members doesn't work, or if there are no family members to contact, seek help from social service agencies. Your state or locality probably has special agency for assisting the elderly, often called "the Department for the Aging." These agencies can either provide services directly to residents to help them care for themselves or refer you to an agency that can help. Ask staffers in your local HUD office if they can refer you to an agency, or check the government listings in your phone book.

You could also try calling a private agency directly. Many private agencies are associated with religious organizations but get funding from government agencies. They offer their services to any elderly person who needs them. For instance, in New York City, the Federation of Protestant Welfare Agencies, Catholic Charities, and the Jewish Association for Services for the Aged all help. You can also try community-based organizations such as Meals on Wheels, which may also get government funding.

If you have trouble locating an agency to help, you can call the Eldercare Locator at 1-800-677-1116 for a referral to an agency in your area. This number is a service of the National Association of Area Agencies on Aging.

How Agencies Help

Here are some examples of how getting for a resident can help:

Housekeeping. An arthritic resident can't tie his garbage bags tight enough. The garbage is attracting cockroaches and rodents. Solution: An agency worker comes in, bags the garbage, and cleans up the apartment.

Money management. A resident has become forgetful and her eyesight is poor. She has several uncashed Social Security checks in her apartment. This resident, who has never missed a rent payment, now owes you for two months. Solution: An agency worker takes the resident to the bank, helps her endorse the checks, deposit them, and write the rent checks.

Personal care. An older man falls asleep after turning on the bathtub faucet. He floods his bathroom and the bathroom below. Solution: An agency worker, trained to take care of an older person's physical needs, comes to help bathe the man.

Alper remembers an 80-year-old resident with Alzheimer's disease who began to wander around without clothes in below-freezing weather. First, management sent a letter to the resident noting the incidents and expressing concern for her welfare. A manager then spoke to the resident about the incidents, but she couldn't remember them when she was lucid. The manager called the resident's family, but they didn't want to be involved. Finally, management called a social service organization for the elderly. After the organization became involved, the woman's daughter became embarrassed and stepped in to help. The woman was able to stay on as a resident with her daughter's supervision.

A safer living situation. Other times, the ending may not be as happy, but at least you'll help the resident live in a more appropriate environment than your site. For example, management consultant Ed Kelley describes an elderly woman who hung newspapers and cans from strings on her ceiling. As she accumulated more and more newspapers, her apartment became a fire hazard.

Management wrote a letter to the resident, then spoke to her about the danger. She refused to remove the papers and strings because she believed they were protecting her from being "super-gassed." Since the resident had no family to contact, management called a state agency. After conducting an evaluation, the agency placed the resident in a home and helped her move.

Tips on What to Say

➡ **Don't diagnose the problem.** When speaking to the resident, family members, or agencies, don't offer your opinion on what the resident's problem is, advises Alper. Simply describe what the resident does. Don't say, "Mrs. Jones is senile and can't take care of herself." Instead say, "We discovered that Mrs. Jones has accumulated 50 garbage bags in her kitchen." And when speaking to agencies, let staff members decide what kind of help to give.

➡ **Describe the danger to the resident, not your site.** When speaking to the resident, family members, and social service agencies, express your concern in terms of the resident. Social service agencies are interested in the welfare of the elderly resident, not in what happens to your site. When you call an agency, describe the problem in terms of the danger the resident poses to himself and other rather than to your physical property.

For example, suppose a resident leaves the gas jets on. When you call an agency, don't say: "I'm afraid the resident may burn down my building." Instead, say something like this: "I understand your agency can help elderly people who are endangering themselves. A resident at my site keeps forgetting to turn off the gas jets on his stove. I'm afraid he may asphyxiate or burn himself, or start a fire and die. I'd appreciate it if you could come to his apartment to investigate."

Three-Step Procedure Helps Avoid Discrimination Lawsuit

Following our recommended three-step procedure for dealing with elderly residents who can't cope can help you avoid fair housing trouble. Here's why:

Under federal law, you must make a "reasonable accommodation" for someone with a disability if he requests one. This means making reasonable changes in rules, policies, practices, or services to give a disabled person equal opportunity to enjoy a dwelling. If you seek to evict a resident with a mental disability before trying to reasonably accommodate him, you could be found to have violated the Fair Housing Act.

Example: The owner of a Section 202 site in North Carolina recently agreed to settle a case with a 90-year-old mentally disabled resident. The owner had tried to evict the resident because she had disturbed neighbors and interfered with management of the apartment complex. The resident claimed that her actions were the result of her mental disability and the owner had failed to reasonably accommodate her. The owner agreed to issue a new lease and to train resident managers about their legal duty to accommodate for mental disabilities [Country Village v. Knudson].

To help you avert a similar outcome, first try our three-step procedure. If you've written and talked to a resident, contracted the family if possible, and gotten in touch with a social service agency for help, that should be enough to back up your decision to evict the resident if problems persist, advises Alper.

Sources:

Mark Alper: Director, Fair Housing Compliance, National Center for Housing Management, 1010 Massachusetts Ave., NW, Ste. 400, Washington, D.C. 20001.

Ed Kelley: President, E.N. Kelley & Associates, 1526 E. 55 St., Chicago, IL 60615.

Legal Citation

Country Village Apts. v. Knudsen: No. 92 CVD 5270 (N.C. Dist. Ct. 12/6/93.)

Appendix 6.6

Making the Decision: When is the Right Time for Facility Care?

It is difficult to know when to begin looking for facility care for a resident with Alzheimer's or a related dementia. The most important thing to remember is that there is no "right" time for everyone. Each person and family situation is different, and there are several factors to consider. To discuss these factors, the RSC may wish to facilitate a meeting including family, care providers, Adult Protective Services (if necessary) and the person with Alzheimer's. Use the checklist below to assess the resident's situation.

➔ What Are The Important Issues?

- Safety
- Nutrition
- Personal hygiene
- Lease-violating behaviors
- Time and energy
- Financial concerns
- Caregiver issues
- In-home options.

Safety

- Does the resident forget or refuse to use safety equipment such as wheelchairs, walkers, or grab bars?
- Is the home environment becoming more difficult for the person with Alzheimer's (e.g., stairs, accessible doors, dark hallways)?
- Has the resident had accidents with the stove, appliances, or other household items?
- Has the person with Alzheimer's had trouble getting around the house without falls or extensive help walking?
- If the resident smokes, has he or she had smoking accidents (for example, forgetting to extinguish a cigarette or cigar, burning holes in clothing)?

Nutrition

- Does the resident have trouble preparing meals or eating independently?
- Is it difficult to encourage the resident to eat appropriate, nutritious foods?
- Is the resident having health problems associated with poor nutrition – vitamin deficiency, dehydration, weight loss, illness?

- Has eating and swallowing become difficult for the resident with Alzheimer's?

Continued

Personal hygiene

- Is it difficult for the resident to get to the bathroom when needed?
- Is the resident with Alzheimer's unwilling or unable to bathe?
- Is the resident unwilling or unable to change clothing when needed?
- Is the resident unable or unwilling to help with personal care tasks?
- Have care needs for the resident become too difficult or too demanding for his or her spouse or caregivers?

Behavioral concerns

- Has the resident ever wandered away from home or been lost?
- Is the resident combative, suspicious, angry, or refusing care?
- Has the resident physically harmed himself, or you, or anyone else in the past?

Time and energy

- Does the resident need help with most Activities of Daily Living (such as eating, bathing, dressing, personal hygiene)?
- Do housekeeping duties need to be done so frequently that care becomes an excessive demand?
- Is the spouse or caregiver struggling with fatigue, depression, or stress?

Access to in-home care

- Can the family afford sufficient in-home services to address his or her needs?
- Can home-care agencies reliably staff the resident's care needs?
- Have the financial strains of caregiving put a strain on the family's budget?
- Can the family provide more care for the resident?

Caregiver issues

- Is the spouse or caregiver's health at risk as the result of caregiving responsibilities?
- Is the spouse or caregiver unable to manage the household, pay bills on time, etc.?
- Is there frequent conflict between household or family members related to caregiving issues?
- Have in-home services such as housekeeping, personal and companion care, or overnight care been unsuccessful?
- Does the resident with Alzheimer's resist attending adult day programs?

If you answered "yes" to many of these questions, you, the resident, and the resident's family may need to begin thinking about alternative care options. These are just some of the factors to consider when making this difficult decision. Individual personalities, family, history, and outside support should always be a part of the decision.

Source: Amelia Schafer Grundy, Oregon Trail Chapter, Alzheimer's Association, Inc.

Chapter 7

Involving the Police and Adult Protective Services

Abuse, neglect, and exploitation happen to thousands of adults in Maine every year. Many people are uncomfortable talking about these problems, especially if the abuser is a family member or friend. Help is available if people are aware of the problem and take steps to report it.

Police/Fire/Rescue

In an emergency situation, housing staff should follow the protocol outlined in Chapter 6. The 911 responders (police, fire and/or emergency medical) will know what to ask about the situations and what protocols to follow.

There are, however, several steps that housing staff can take before a crisis arises to establish an effective working relationship with local public safety officials.

Contact police, fire and EMS departments and give them a general profile of the population housed in your building.

Request in-service education for your staff to introduce them to public safety officials and educate them on what they can expect after placing a call to 911. Ask them for advice on how staff can best respond to a crisis situation.

Host a "Meet the Police" community policing event in your building. Encourage residents to attend. Ask the police to offer free photo taking for emergency identification and notification cards to have on file at the police station and with the building manager.

Adult Protective Services

The Maine Department of Human Services' Bureau of Elder and Adult Services is responsible for providing or arranging for services to protect adults who are unable to protect themselves from abuse, neglect, or exploitation. Adult Protective Services staff also petition for Public Guardianship and/or Conservatorship of incapacitated adults when all less restrictive alternatives have failed.

Adult Protective Services clients are victims of physical abuse, unreasonable confinement, neglect, financial exploitation, and sexual abuse. Verbal abuse, intimidation, and deprivation of food, water, or medical care are other forms of danger to which clients are subjected. Danger may also include self-abuse or self-neglect. APS clients include the homeless, the mentally ill, those with substance abuse problems, the frail elderly, and those with medical problems or persons with disabilities.

Abuse

Abuse includes actions that result in bodily harm, pain or mental distress. Examples of abuse are:

- Pushing, hitting, shaking, pulling hair
- Tying to a bed or chair, or locking in a room
- Forcing into sexual activity
- Giving the wrong medicine or too much medicine on purpose
- Denying visits with friends or family
- Harassment or verbal threats.

Neglect

Neglect is a failure to provide care and services when an adult is unable to care for himself or herself. Neglect may be at the hands of someone else or it may be self-neglect. Neglect includes failure to provide:

- Adequate shelter
- Personal care
- Medical attention or necessary medication
- Necessities such as glasses, dentures, hearing aides, walkers.

Exploitation

Exploitation is illegal or improper use of an adult's money or property for another person's profit or advantage. Examples of exploitation include:

- Forcing an adult to change a will or sign over control of assets
- Forcing an adult to sell or give away property or possessions
- Keeping the adult's pension or social security check.

Who may receive these services?

Any dependent or incapacitated adult who may be in danger of abuse, neglect or exploitation may receive assistance from Adult Protective Services. A dependent adult is a person who is wholly or partially dependent upon other people for care and support, either emotional or physical, and who would be in danger if that care and support were withdrawn. An incapacitated adult is a person who lacks sufficient understanding to make or communicate decisions about his or her own person or property. These adults may need someone else to make some or all of their decisions for them.

What can adult protective services staff do?

- Investigate reports of abuse, neglect or exploitation
- Arrange services to help make adults safe

- Arrange services to allow adults the most personal freedom possible
- Seek Guardianship and/or Conservatorship of adults who are unable to make these decisions for them.

Guardianship/Conservatorship

Guardianship/Conservatorship provides protection and care for incapacitated adults. Only a Probate Court can declare an adult to be incapacitated and appoint a guardian or conservator. The court uses the opinion of a licensed physician or psychologist in making this decision.

Any able and willing adult may be a guardian or conservator. If there is no private individual able and willing to assume the responsibility, then the Department of Human Services may be appointed a public Guardian or Conservator.

Making reports

Adult Protective Services Intake is available 24 hours a day. If you suspect that an incapacitated or dependent adult has been abused, neglected or exploited, or if an incapacitated adult needs a guardian or conservator and there is no private person willing or suitable to serve, please call APS at 1-800-624-8404. You will be asked to provide the information you know about the adult. The information requested will include personal identifying information as well as any information you have on the adult's mental capacity, physical dependency, and danger or risk of danger concerns. The more information you can provide, the better the intake staff can assess the situation and make the appropriate referrals.

Talking To Older Victims Of Domestic Violence

➔ Ask about abuse

Lead into questions about abuse: "Because many of the people I work with are hurt by family members, I ask questions about relationships and abuse."

The questions may include:

- How are things going with your spouse (or adult child)?
- Are you getting out with your friends?
- Are you afraid of your spouse (or other family member)?
- Does anyone ever threaten or force you to do things you do not want to do?
- Have you ever been forced to do sexual acts you do not wish to do?

If the answer to any of the above is "Yes," ask for more information and ask questions such as, "How are you staying safe?"

If the answer to all of the above is “No,” you may wish to make a statement like, “If a family member ever does hurt you, or you know someone who is being hurt, there are people who can help. Feel free to contact me for information if you ever need it.”

➔ Things to listen to and watch for

From a potential victim . . .

- Has repeated “accidental” injuries
- Appears isolated
- Talks about or hints at being afraid
- Considers or attempts suicide
- Has a history of substance abuse (including prescription drugs)
- Presents as a “difficult” patient or client
- Has vague, chronic complaints
- Is unable to follow through on treatment plans or medical care
- Exhibits severe depression.

From a potential abuser . . .

- Is verbally abusive to staff in public or is charming and friendly to service providers
- Says things like “he’s difficult,” “she’s stubborn,” “he’s so stupid,” or “she’s clumsy”
- Attempts to convince others that family member is incompetent or crazy
- Is “overly attentive” to the family member
- Controls the family member’s activities
- Refuses to allow interview or exam to take place without being present
- Talks about the family member as if he or she is not a person.

Intervention: At Least Do No Harm

- ➔ DO everything possible to give the victim a sense of hope by:
 - Believing the account of the abuse
 - Sharing that abuse can happen to anyone and the victim is not alone
 - Affirming that the victim is not to blame for the abuse
 - Planning for safety or finding someone who can
 - Offering options and giving information about resources or finding someone who can
 - Allowing the victim to make decisions about next steps (returning power to the victim)
 - Keeping information shared by the victim confidential
 - Documenting the abuse with photographs, body maps, and victim statements.
- ➔ DO NOT do anything that further isolates, blames, or discourages victims, such as:
 - Telling the victim what to do (e.g., “you should leave immediately”)
 - Judging a victim who returns to an abusive relationship
 - Threatening to or ending services if a victim does not do what you want
 - Breaking confidentiality by sharing information with the abuser or other family members

- Blaming the victim for the abuse (“If only you had tried harder or done this, the abuse might not have happened”)
 - Reporting abuse to the authorities without permission from the victim (unless mandated by law). If you are a mandated reporter, tell the victim what you are doing and why. Help the victim with safety planning or find someone who can.
 - Document opinions (“He’s drunk and obnoxious,” or “She’s hysterical and overacting”). These statements are opinions and may not be accurate. However, they can be used against a victim in court.
- ➔ DO NOT collude with the abuser and give him or her more power and control by:
- Accepting excuses from the abuser and supporting the violence (“I can understand how much pressure you are under. These things happen.”)
 - Blaming drug abuse, stress, anger, or mental illness for the abuse. Abusers must be held accountable for their actions.
 - Minimizing the potential danger to the victim or yourself if you offer help. Arrange for appropriate security for the victim and your staff when working with potentially lethal batterer (e.g., has made homicidal/suicidal threats or plans, owns weapons, is fixated on victim).

Work Collaboratively

- To learn more about potential interventions, contact local domestic abuse and/or sexual assault, victim/witness, or call **Adult Protective Services at 1-800-624-8404**, 24-hours a day.
- With the victim’s permission, refer to appropriate agencies for assistance.
- Use experts in a variety of fields as case consultants on difficult cases. Bring challenging cases to a multi-disciplinary team for review, ensuring client confidentiality.

Resources And Further Reading

1. Maine Community Policing Institute, The University of Maine at Augusta, 46 University Drive, Augusta, ME 04330. Originally funded through a grant from the U.S. Department of Justice in 1997, MCPI has evolved into a self-sustaining organization devoted to delivering education, training, and technical assistance with community policing programs. For information, contact Noel March, MCPI Director, at 1-800-734-2991, ext. 3480.
2. TRIAD, a 3-way effort among local sheriffs' offices, police departments, and the American Association of Retired Persons (AARP) aimed at reducing victimization of older citizens and enhancing delivery of law enforcement services to this population. For more information about TRIAD services and programs in your area, contact your local police department.
3. *Adult Abuse, Neglect and Exploitation*, published by the Bureau of Elder & Adult Services. For more information, or to order a copy, call 1-800-262-2232, or visit their web site at www.state.me.us/dhs/beas

Chapter 8

Legal and Financial Issues

*The material in this chapter was written and prepared by Timothy M. Vogel, Esq., of Vogel & Associates in Portland, Maine, a law firm specializing in elder law. The material is designed to provide authoritative information regarding the subject matter covered. The material is provided with the understanding that it does **not** constitute individual legal advice. Your specific individual circumstances will dictate the appropriate legal and financial advice for you. If you desire direct legal advice regarding your circumstances, you should directly consult an attorney familiar with this subject matter. If financial advice or other expert assistance is required, the services of a professional should be sought.*

What This Chapter Will Cover

- Who can participate in decision making when the resident's ability to make and carry out decisions declines due to Alzheimer's disease, dementia or other accident or illness.
- The decision-making assistance of an Agent with Power of Attorney, as well as a Probate Court appointment of a Guardian and Conservator.
- The best methods to intervene to direct and control the behavior of the Alzheimer's or dementia-impaired resident within the context of the resident's individual decision-making ability and the legal decision-making authority of the Agent under the Power of Attorney, as well as the Guardian and Conservator.
- Understanding the law to avoid negligent liability.
- Operating your business to protect yourself and your residents.

Advance Directives: Appointing Legal Decision-Makers

Maine law, as well as our society in general, places great importance in individual autonomy and the respect due to each person's ability to make decisions. We respect adults to run their own lives and to make decisions for themselves. It becomes a difficult situation to which we must adjust when a person's decision-making ability declines due

to Alzheimer's disease, another dementia condition, or an accident or illness. All of us should identify in advance the persons we want to assist us if we become incapacitated and they cannot make decisions on our own.

It is best for the resident to voluntarily appoint a trusted individual to be available to assist with making or carrying out decisions if the resident becomes incapacitated. The most appropriate legal documents in this situation are called **Advance Directives**, so called because in *advance* of something happening to a person that individual *directs* who should have authority to assist the person and in what fashion.

The most common Advance Directives are the **Durable Financial Power of Attorney** (DFPOA) and the **Power of Attorney for Health Care** (POAHC), including **Living Will** language that specifies the extent to which medical care is to be provided or withheld during a terminal condition. These documents are sometimes collectively referred to as a **Durable Power of Attorney** (DPOA).

➔ **Everyone should have both a Durable Financial Power of Attorney and a Power Of Attorney For Health Care to help him or her if they become incapacitated and unable to make decisions without assistance.**

Spouses, solely through marriage, have no legal right to make legal, financial or medical decisions for the other spouse, except in the limited circumstances as surrogates under the Maine Uniform Health-Care Decisions Act (UHCDCA). Spouses have no legal right to make financial or property decisions for the other spouse, except for those accounts or property that are held jointly. Physicians and health care institutions may consult and cooperate with the healthy spouse. However, if a difference of opinion develops as to proper medical care for the patient, the physician or health care institution may stress that the spouse has no legal authority to make health care decisions for the patient.

➔ **It is essential to make legally adequate provisions regarding who will have legal and decision-making authority at a time when the older adult is mentally able to grant such authority.**

Important Power of Attorney Terms You Should Know

- The legal document is generally called the DURABLE POWER OF ATTORNEY (DPOA). This applies to both a DURABLE FINANCIAL POWER OF ATTORNEY (DFPOA) and a POWER OF ATTORNEY FOR HEALTH CARE (POAHC).
- The person (resident) signing the document is the PRINCIPAL.
- The Principal appoints the AGENT (also known as ATTORNEY-IN-FACT) to have authority to assist the Principal with making or carrying out decision making. Frequently the Agent is the Principal's trusted spouse, child, relative or close friend.

- The Principal should appoint a primary Agent and a SUCCESSOR AGENT or Agents. This is important in case the primary Agent is unable or unavailable to assist the Principal. It's generally a good idea to list the Successor Agents in order of preference or ability, and to have them serve as Agent if the person listed prior to them becomes unable or unavailable to assist the Principal. Sometimes two or more Agents will be authorized in a DPOA to act at the same time as co-Agents. This runs the risk that one of the Agents may take actions on behalf of the Principal without informing the other Agent. When two or more Agents act as cross-purposes frequently they cause great difficulties.

Conditions Required For a Valid Power of Attorney

- The Principal (resident) must be aware of the matters that concern him or her, such as money, property and medical issues. It is not necessary that the Principal know the exact total in the bank account, but the Principal must know in general the matters involved with his or her life.
- The Principal must be able to select who he or she wants to be primary Agent and successor Agents. Many persons in the early stages of Alzheimer's Disease or another dementia condition have sufficient mental ability to have legal capacity to execute a valid Power of Attorney.
- It is the professional duty of the lawyer to evaluate the person's mental condition and the applicable standard of law to determine if person has the legal capacity to execute the Power of Attorney.

Important Facts About the How Power of Attorney Works

1. The Principal can continue to act for him or herself, and can amend or revoke the DPOA, as long as the principal possesses mental capacity.
2. Both the DFPOA and the POAHC documents can become effective when they signed. Then there will be no question that the Agent has authority to act on behalf of the Principal. However, this approach establishes the Agent with authority to act for the Principal while the Principal continues to act for him or herself. This may be no problem if the Principal trusts and communicates with the Agent. There may be difficulties if the Principal and Agent fail to communicate, or if the Principal becomes paranoid as result of declining mental abilities. As another option, the document can be written to require that written proof of the Principal's incapacity must be produced before anyone may respect the DFPOA or POAHC to be valid. While this may offer the Principal a sense of security, it may prove difficult for the Agent to prove his or her authority to act for the Principal, especially in an emergency.
3. The DPOA should be DURABLE. That is what the "D" in DPOA represents. Durable means that the document remains valid in spite of any future physical or mental disability the principal might suffer. The document is durable when it

contains language stating that the validity of the document is not affected by the subsequent physical disability or mental incapacity of the Principal, or by the expiration of a set amount of time. Frequently, when the document has such language and is thus durable, the document will have the word “Durable” in its title.

4. For the DFPOA, Maine law requires that warning notices must be included in the document for documents signed after September 18, 1997. Such notices have specific language that must be used to notify both the Principal and the Agent of the serious nature of the DFPOA, as well as their rights and responsibilities. The Agent is informed that civil and criminal penalties exist for any financial abuse or mismanagement by the Agent. This warning language requirement does not render ineffective a valid DFPOA that was executed prior to September 18, 1997.
5. The DFPOA covers financial matters and legal decisions. If the Agent is to have authority to manage the Principal’s assets to eventually qualify for Medicaid, specific asset-gifting authority must be included in the DFPOA.
6. The POAHC covers medical and health care decisions, and authorizes the Agent to have access to medical information concerning the Principal. Under Maine law, the POAHC also incorporates medical decisions for patients in a terminal medical condition that had been previously controlled under Maine’s Living Will law. The Principal may include in the POAHC his or her decision that when in a terminal medical condition, he or she does not wish to receive medical treatment or intervention that only prolongs the dying process.
7. In the DFPOA, the Principal can nominate a person, usually the Agent, to be the Guardian or Conservator for the Principal. This nomination is useful in the unlikely event that someone would petition the Probate Court to appoint a Guardian or Conservator for the Principal. Such a request that the Probate Court appoint a Guardian or Conservator is uncommon because almost always the DFPOA and POAHC grant the Agent sufficient authority to assist the Principal without having to resort to the Probate Court. If such a case goes before the Probate Court, it is because either the DFPOA or the POAHC are invalid or inappropriate for the circumstances, or because there has been a family dispute.
8. Under both the DFPOA and POAHC, the Agent is acting in a position of trust with certain responsibilities. When the Agent handles money and property for the Principal, the Agent must keep accurate records of how the funds are used and the properties managed. In most cases, it is sufficient to pay expenses by check and to keep copies of receipts and other financial documents. The Principal’s money and property must be used for the benefit of the Principal, and not the benefit of the Agent. The Agent must avoid financial transactions that place the Agent in a conflict of interest with the Principal. The Agent has the same fiduciary duty to the Principal that a trustee has to a beneficiary. The Agent must have sufficient records to be ready to report on the Principal’s finances and property to a successor Agent, a Conservator

that might be appointed by Probate Court, or to a Personal Representative who will be appointed to represent the Principal after the death of the Principal.

Guardianship and Conservatorship

- ➔ **Guardianship and Conservatorship are Probate Court Orders that occur when the Court determines that an “allegedly incapacitated person” should be treated as a “protected person.”**
- A **Guardianship** is established when the Probate Court appoints a Guardian over a person. The Court must determine that the protected person is unable to make or communicate responsible decisions concerning himself or herself. The Guardian has the responsibility and authority to supervise and control medical, health care and residential matters concerning the protected person.
- A **Conservatorship** is established when the Probate Court appoints a Conservator over a person. The Court must determine that the protected person is unable to make or communicate responsible decisions concerning his or her property or finances. The Conservator has the responsibility and authority to manage, supervise and control the real estate, financial, investment, personal property and income matters concerning the protected person.
- The Guardian and Conservator may be the same or different persons. The appointment of the Guardian and Conservator may be pursued as separate or combined actions in Probate Court.

Some Important Points About Guardianship and Conservatorship

If a resident with Alzheimer’s disease or another dementia condition is involved with the Probate Court in legal actions of Guardianship and Conservatorship, it will most likely be an aggravated situation, and quite possibly an emergency. If the resident and the family have taken a prior opportunity to plan for decision making authority in light of the resident’s declining decision making ability, most likely there will be a DFPOA and POAHC in place.

If petitioning the Probate Court becomes necessary, it is most likely because there are no Power of Attorney documents in place, or because the Power of Attorney documents that exist are not valid or are inadequate for the resident’s needs. For example, there may be a medical emergency where no one has authority to authorize necessary medical treatment. If a Power of Attorney exists it might be invalid or inappropriate for one of several reasons:

- The DFPOA was signed after September 1997 and lacks the Notice to Principal and Notice to Agent language required by Maine law.

- ☒ The DFPOA was not notarized. Maine law does not require that the DFPOA be signed by witnesses, but it is best to have it signed by 2 witnesses.
- ☒ The POAHC was not signed by 2 witnesses. Maine law does not require that the POAHC be notarized, but it is best to have it notarized.

The Probate Court may also intervene if the Power of Attorney document is not appropriate for the resident's circumstances. For example, the DFPOA may lack language permitting the Agent to make gifts when such a tactic would be appropriate for tax or Medicaid planning strategies. Or, the primary Agent may have become unable to assist the Principal and the document does not provide for any successor Agent, or the successor agent is not the appropriate person to assist the Principal. There might also be the situation where the primary Agent must sign a deed for the Principal and the original document DPOA cannot be located. The Registry of Deeds will accept only an original DPOA.

Even where the Principal has signed a valid, appropriate Power of Attorney, the Principal can continue to act on his or her own authority, ability and initiative after signing the DPOA. This may cause a situation where the Agent is attempting to assist the Principal, but the Principal takes inappropriate and possibly dangerous action on his or her own. While petitioning the Probate Court to appoint a Guardian or Conservator is usually avoided because of the time, expense and family tension it involves, sometimes seeking the appointment of a Guardian or Conservator is necessary.

The significant advantage of the Probate Court appointment of a Guardian or Conservator is that it is a court order that the protected person and the institutions dealing with that person must honor. The court order cannot be changed without returning to Probate Court and convincing the Court that there are good facts and law that support changing the court order. When the Principal resists care, many institutions will require that a Guardian and/or Conservator be appointed.

Finally, there may be a major dispute involving the protected person's care, residence or financial management. Such a dispute may involve family members, health care providers or creditors. These disputes may become so intense that the parties have to present their facts and arguments to the Probate Court and let the judge decide whom to appoint as the person's Guardian and Conservator that will act in the person's best interests.

How The Court Appoints Guardians And Conservators

While residents may not frequently be involved with a Guardian or Conservator, several points should be understood about the process. The Petitioner is an individual, usually represented by a lawyer, who petitions the Probate Court to appoint a Guardian or Conservator for an "Allegedly Incapacitated Person" (AIP). The Petitioner must establish that the AIP suffers from a physical or mental condition that prevents the AIP from making reasonable decisions about his or her person or property.

There may be an emergency hearing or a regularly scheduled Probate Court hearing after formal legal notice to all concerned. A physician or psychiatrist must sign a court statement that the protected person is unable to make reasonable decisions regarding self or property. The Probate Court will appoint a nurse or social worker as a “Visitor” to investigate and report on the protected person’s mental and physical condition, the care arrangements, and the suitability of the proposed Guardian and Conservator.

If a resident is an AIP, the Visitor will likely interview someone involved with the person’s housing in order to report to the Probate Court as to the AIP’s present and recommended future residential needs. A Guardianship and Conservatorship Plan must be submitted to the Probate Court outlining care arrangements for the protected person.

If the Guardianship/Conservatorship Petition is unopposed by the AIP or anyone else, then Guardian and / or Conservator is likely to be appointed by the Probate Court within one court hearing if it is a regular petition, or within two hearings if it is an emergency petition. If the Petition is contested by the AIP or by any other person or institution considered an interested party to the court action, it may become a complex, lengthy and expensive trial. If that develops, someone from the AIP’s housing may be called as a witness to describe the facts of the housing situation and how it supports or contradicts the need for the resident to have a Guardian or Conservator.

If there is a dispute as to who should be appointed Guardian or Conservator, Maine law gives priority to a person who is otherwise competent and able, and who has been nominated in writing by the AIP when the AIP was mentally competent. This sort of appointment is commonly included in a DFPOA or POAHC. If there is no one nominated in writing, then the order of priority is the AIP’s spouse, parent and then adult children.

➔ **It is important to understand the behavior and condition of your residents who might be developing Alzheimer’s disease or another dementia condition. You need to understand Power of Attorney, Guardianship and Conservatorship as legal devices that allow for decision making for such persons. However, it is most important to attempt informal assistance and problem resolution for such persons.**

Your Role In Guiding Decision-Making Arrangements

If you suspect that a resident is showing signs of Alzheimer’s or a related dementia, it is important to make sure that appropriate legal arrangements are planned. A meeting with the resident and family members is frequently the best place to begin. Addressing problems early may avoid costly and stressful legal disputes later. Frequently problems can be solved and strategies developed which respond to the resident’s changing mental abilities, memory and behavior. This is the time to urge the family to consult with an Elder Law attorney to secure a valid and appropriate DFPOA and POAHC. It may be possible to work with the family to arrange for the resident’s bills to be promptly paid and for mail to be forwarded to someone with the ability and authority to appropriately respond.

- As the resident's condition develops, review how long the current housing and services will meet the resident's care needs. Plan for an appropriate referral and transfer to an appropriate care setting, most likely an assisted living facility that focuses on dementia care.
- If the resident's situation deteriorates, and it is not possible to work with the resident and family members to make a transfer to an appropriate facility, it may be necessary to pursue eviction as a last resort. You should consult with housing management and a lawyer about policies and procedures to follow in such cases. For many types of government-subsidized housing it is necessary to establish good cause to evict the tenant. Try hard to avoid an eviction, but if there are no alternatives, follow the legal procedures that respect the rights of both the resident and housing management.
- One final note regarding some of the options for the spouse of the resident with Alzheimer's disease or another dementia condition. The spouse is usually the person with the largest burden in caring for such residents. The spouse thus needs as much support as possible from the family, service providers and housing. The needs of the spouse should be considered in developing a transfer strategy for the Alzheimer's/dementia resident. Frequently the spouse will remain in housing when the Alzheimer's/dementia resident transfers to an assisted living facility. Sometimes the spouse is also appropriate for transfer to assisted living. If the Alzheimer's/dementia resident is appropriate for Medicaid in either assisted living or nursing home care, it is possible to protect certain amounts of the family assets and income for the healthy spouse. It is appropriate to suggest that the healthy spouse be referred to an Elder Law attorney familiar with financing assisted living and nursing home care through Medicaid, as well as Medicare, family funds and long term care insurance.
- Elder law attorneys in your area are a good source of information and support for your residents who are involved with many of these issues. **You can locate an elder law attorney in your area through the Maine State Bar Association, 622-7523.** Invite the elder law attorney to your housing facility to present a short presentation for residents on Powers of Attorney and other issues pertinent to Alzheimer's/dementia residents and their families.

Understanding The Law To Avoid Negligence Liability

Many persons and institutions today fear that they will be unduly sued on a claim that they negligently injured someone. These fears also exist among housing providers. The best way to protect yourself from negligence law suits is to understand how the law imposes liability for negligence, and on whom and in what circumstances.

- ➔ **Negligence is the failure to prevent a foreseeable injury. To establish a successful claim of negligence, the plaintiff must prove 3 elements.**

- 1. Breach of duty.** This is defined as a failure to observe the **standard of care** established for the conduct in question. The standard of care is what a reasonably prudent person would have done in the same or like circumstances. The standard of care may be established by a combination of expert witnesses, internal business policies and procedures, governmental rules and regulations, or what courts have decided the standard of care is in similar circumstances.
- 2. Proximate cause.** The breach of duty must have been the **proximate cause** of the injury that was reasonably foreseeable. The proximate cause must be foreseeable. The breach of the standard of care must be the cause of the injuries. That is there must have been no intervening actions or circumstances that caused the injuries independent of the breach of the standard of care.
- 3. Damages.** The injury must have caused **damages** for which the person can be monetarily compensated. The person must have suffered some physical, mental or property damage that is appropriate for the award of monetary compensation. **Compensatory damages** are awarded by the courts to compensate the injured person for expenses arising directly from the injury and recovery. **Punitive damages** are awarded because the person or company that caused the injury acted intentionally or with gross negligence.

Who Can Be Liable For Negligence?

Anyone who had anything to do with the situation can be held individually responsible if the 3 elements of negligence are established regarding his or her conduct.

- **Respondent Superior.** The employer is held responsible for the actions of an employee, unless it can be clearly shown that the employee acted outside of the scope of his or her authority. Your liability may be lessened if you use an **Independent Contractor**, but you give up much ability to control an independent contractor.
- **Corporate Liability.** Corporate assets are at risk under respondeat superior or if the corporation fails to properly conduct its business or supervise and control its employees. Corporate liability is usually limited to corporate assets, but **corporate directors and officers** may be personally liable for their failure to properly control and direct the corporation. In Maine, **directors and officers of a nonprofit corporation** are immune from negligent actions, but not from intentional actions. However, such immunity does not protect against the costs of defending a law suit.
- **Apparent Agency.** When a business provides a product or service to the public, that business is liable to the public for its actions. However, if the public **reasonably** believes that another agency or business is providing the product or service, then the **second business** may be liable for any injuries caused by the product or service.

Take Steps To Protect Yourself

Be aware that your residents understand who is providing them with products and services. You do not want to be in the situation where you have no control of the product or services that your residents are receiving, but are liable for any injuries your residents may suffer because they reasonably believe that you are providing the products and services.

Keep clear and regular business records. Good business records can establish the facts concerning a disputed incident. Good business records can establish the standard of care in your favor. Non-existent or careless business records can show that your business is negligent. Inaccurate or thoughtless statements in your business records can be the strongest admissions against your interest.

Be clear with **BOTH** your service providers and with your residents as to who is providing what services, under whose control and under what conditions. You should set the terms by which both your service providers and your residents understand that the product and service are being delivered. Do not let others dictate the terms on which you deliver your products or services. Visualize how both service providers and residents perceive your operations. What is clear to you may be seen in a very opposite light by someone who is injured, or by a court several years from now.

Discuss your products and services with your insurance agent and understand your insurance coverage, including the costs of a legal defense.

Be clear with your residents, especially in the language that is used in your resident agreements and disclosures. **A waiver will not protect you from negligence liability if an injured resident brings a claim against you.** A waiver signed by your residents may show that they have been informed of the facts of the situation, or that they chose to act knowing certain facts. However, a waiver will not by itself be total protection against liability for negligence.

You assume a much smaller risk if you properly operate a consumer-driven, service-delivery model that emphasizes a resident's independent decision making ability. Your greatest liability is when you make decisions for the resident.

Negligence Claims Can Be Limited In Several Ways

Statute of Limitations. The law limits the length of time a plaintiff has to file a complaint in court against you following the injury. In Maine, the general statute of limitations for injuries is 6 years.

Assumption of Risk. If a person makes an informed choice to assume some risk of injury when choosing a service, that person's ability to recover for an injury may be limited under the law of comparative negligence.

Comparative Negligence. If the injured person contributed to the cause of the injury, a court will reduce the damage award according to the percentage that the injured person was responsible for the injury.

Conclusion

There is a great demand for the services residents want and need. Do not become frozen in your actions because of undue concerns for liability. While there is no way to entirely avoid the risk of being sued, there are many things you can do to vastly reduce that risk.

Understand the special circumstances and needs of persons with Alzheimer's disease and other dementia conditions. Work with such residents and their families to recognize their conditions and limitations. **Know how Power of Attorney, Guardianship and Conservatorship can help residents who have trouble with decision making.**

Make the continued stay of residents with Alzheimer's disease and in your housing as positive as possible for as long as possible. Help identify when they need to move into an assisted living facility, or another location that can provide a higher level of care. Discuss with the resident, spouse and family where appropriate care for the resident can be located. Encourage your residents and their family to utilize the services of the Alzheimer's Association.

Develop a good consumer-driven supportive services model of product and service delivery. Utilize a service coordinator. Establish **written** policies and procedures. Inform residents of all aspects of the program in writing.

Resources And Further Reading

1. Vogel & Associates, 550 Forest Avenue, P.O. Box 3649, Portland, Me 04014-3649, a law firm focusing on Elder Law. For more information, contact Timothy M. Vogel, Esq., at 207-761-7796 or send an e-mail to tvogel@maine-elderlaw.com
2. *Aging: Taking Care of Business*, published by the Maine State Department of Human Services, Bureau of Elder and Adult Services, January 2000. To order copies, call the Bureau toll-free at 800-262-2232, or visit their web site at www.state.me.us/dhs/beas

Chapter 9

Creating a More Dementia-Friendly Environment

As elders age in place, many will experience dementia either in themselves or their spouses. A dementia-friendly environment allows these residents to remain independent far longer than an unfriendly environment. Dementia-friendly designs accommodate both the sensory changes associated with normal aging and the cognitive changes associated dementia.

General Principals of Good Design for Older Persons

Body System	Changes Commonly Observed	Design Implications
Vision	<ul style="list-style-type: none">• Less light reaches retina• Slowed adjustment to changes from dark to light• Altered color perception• Greater sensitivity to glare	<ul style="list-style-type: none">✓ Use brighter illumination✓ Provide a place to stand or sit at entrances and brighter light at transition areas✓ Blues and green are hard to differentiate✓ Use matte treatments on surfaces and control light from windows
Hearing	<ul style="list-style-type: none">• More difficulty hearing higher frequencies (including voices)• Reduced ability to discriminate between sounds	<ul style="list-style-type: none">✓ Use sound-absorbing materials, particularly in public areas✓ Minimize unnecessary noise
Thermal regulation	<ul style="list-style-type: none">• Increased sensitivity to drafts and chills	<ul style="list-style-type: none">✓ Keep temperatures warm✓ Seal windows and doors
Tactile sensation	<ul style="list-style-type: none">• Decreased manual dexterity	<ul style="list-style-type: none">✓ Avoid small door handles, latches, and key rings
Musculoskeletal	<ul style="list-style-type: none">• Diminished strength, more difficult to rise from a chair• Lowered stamina, cannot walk as far	<ul style="list-style-type: none">✓ Chairs should have arms that extend to front edge of seat and no cross bar between front legs✓ Provide seating along paths
Balance	<ul style="list-style-type: none">• Greater difficulty maintaining balance, particularly in the dark or on uneven surfaces	<ul style="list-style-type: none">✓ Use night-lights✓ Provide things to hold on to near bed, bath, and toilet
Gait	<ul style="list-style-type: none">• Feet raised less during walking	<ul style="list-style-type: none">✓ Fix uneven floors and tape down rugs

Additional Environmental Design Tips For Dementia

Doors and hallways

- Hang pictures, photos, or novelty items to personalize apartment doors to help residents differentiate their living space from everyone else's.
- Use realistic graphics and keep signs simple, because the person may not be able to comprehend complex language.
- Use prominent numbers and distinctive artwork at the entryway to elevators to help residents distinguish one floor from another

Hallways and floors

- Make hallways distinct by placing artwork or pieces of furniture at key intersections (if allowed by code).
- Provide handrails in hallways and grab-bars in bathrooms.
- Make sure that floors are not slippery or do not have the appearance of being slippery by being highly polished.
- Provide gradual transitions when changing flooring material (e. g., a transition from a hard surface to carpeting) to minimize falls, and provide a handrail or other support in these areas.
- Avoid using very dark-colored rugs or dark color patches on a patterned rug. The person may interpret these areas as a hole and either attempt to step over (risking a fall) or refuse to traverse (freezing in place).
- Avoid wallpaper and borders with strong, busy patterns.
- Avoid the use of mirrors or mirror tiles.
- Have baseboard treatment (often vinyl) match the color of the lower part of the wall as opposed to the floor.

Windows and Steps

- Place contrasting colored rugs in front of doors or steps to help the individual anticipate staircases and room entrances, but avoid very dark colors.
- Apply colored decals to glass doors and large windows.
- Place a colored stripe on the edge of steps to help the person see each step.

Kitchen and Appliances

- Provide separate power controls for stoves and ovens, and consider automatic shut-off devices for appliances such as an iron, toaster oven and coffee maker.

Lighting

- Create an even level of lighting. Add extra lighting in entries, outside landings, areas between rooms, stairways and bathrooms because changes in levels of light can be disorienting to the individual with Alzheimer's.
- Diffuse bright light. Reduce glare by covering windows with blinds, shades or sheer draperies to block bright sunlight. Avoid using bare light bulbs or clear decorator bulbs without shades.
- Install special lighting. Place night lights in hallways, bedrooms and bathrooms to prevent accidents and reduce disorientation. Illuminated light switches and timers for lights in these areas can also assist the person at night.

Bathrooms

- Locate a toilet adjacent to each public area.
- Increase the contrast between the toilet and floors and walls by changing the color of the flooring or walls or by using a colored toilet seat.
- Increase the contrast between the sink and counter top.
- Use large, easily visible sink handles.
- Set hot water temperatures at 120 degrees and consider installing automatic-mixing or anti-scalding devices to the faucet.

Furnishing

- Minimize crowded furnishings and visual clutter. It will confuse and overstimulate the person.
- Maximize the contrast between the floor and chairs (particularly seats) and between the floor and table surfaces by differences in both color and hue.

Sources

1. *Key Elements of Dementia Care*, Alzheimer's Association and Related Disorders Association, Inc., 1997.

Resources A nd Further Reading

1. *The Complete Guide to Alzheimer's-Proofing Your Home*, by Mark L. Warner, Purdue University Press, 1998.
2. *Homes That Help*, by Richard V. Olsen, et al., New Jersey Institute of Technology, 1993.

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A. Ricker Hamilton, *Department of Human Services, Adult Protective Services*
Linda Hooker, *Oxford County Sheriff's Department*
Cynthia Instasi, (formerly) *Eastern Agency on Aging*
Bette Jewett, *Southern Maine Agency on Aging*
Heather MacDonald, *York-Cumberland Housing Management Corporation*
Noel C. March, *Maine Community policing Institute*
Darrell S. Nichols, Esq., *Legal Services for the Elderly, Inc.*
Susan Rovillard, *Home Resources of Maine*
Marilyn Soper, (formerly) *Maine State Housing Authority*
Romaine Turyn, *Maine Alzheimer's Project*
Timothy M. Vogel, Esq., *Vogel & Associates*
Mary A. Weiss, *Woodcock Management, Inc.*

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