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."

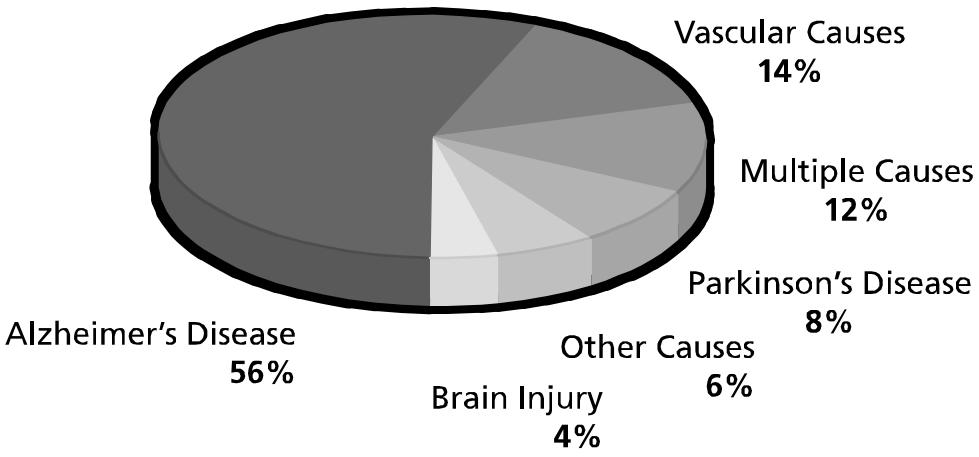
10. Loss of initiative

- 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.

Causes of Dementia[3]



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.

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 difference 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 proton 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.

Continued

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.

Continued

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.

Appendix 2.4

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 . . .)

Anemia (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	▪ Confusion ▪ Vagueness ▪ Suspicion ▪ Poor memory for recent events ▪ Restlessness ▪ Pacing ▪ Agitation	▪ Decreased ability to maintain attention ▪ Disorganized thinking ▪ May have psychotic symptoms like hallucinations and paranoia ▪ Speech incoherent at times	▪ 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

Source: *Case/Care Documentation Guidelines*, Alzheimer's Disease and Related Disorders Association, Inc.

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
- Scolpolamine
- Antispasmodics

Cardiac and Antihypertensives

- Digitalis
- Nitrates
- Procainimide
- 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, Corticosteriods

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 infectous 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.

Continued

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

Stage One: Two-to- four years in duration. During this stage, the individual with Alzheimer's may still be working or living alone.	**Symptoms Include:** ▪ 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
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.	**Symptoms Include:** ▪ 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
Stage Three: During this time, the person with Alzheimer's will be almost entirely dependent on others for	**Symptoms Include:** ▪ 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.	▪ Falls frequently ▪ Difficulty swallowing ▪ May have seizures ▪ Sleeps more ▪ Increased frailty ▪ Probably becomes bedridden

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 were 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 live 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 trails, 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

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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.

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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 rivastigimine (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

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