

Alzheimer's and the Professional Guardian

By Shirley Henderson

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The material in this book should **not** be construed as legal or medical advice. Properly qualified professionals should be consulted for the legal or medical ramifications of any particular fact pattern.

The guardian typically has control of the ward's person and property. This book examines the guardian's role regarding the person of the ward who is an Alzheimer's patient. It does not discuss the guardianship of property. For more details on the latter, see Shirley Henderson, *Ethics and the Professional Guardian*, 2009.

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Chapter 1: What is Alzheimer's Disease?

Why knowledge of Alzheimer's is a critical skill for a professional guardian

Alzheimer's disease is a widespread affliction among older people, creating much of a professional guardian's clientele. A guardian needs to understand

- what the ward is going through
- how that impacts a ward's interaction with the guardian
- how the ward's eventual inability to communicate impacts the guardian's responsibilities
- what to look for to make certain the ward is receiving proper care.

What Dr. Mary Pipher wrote of old age is equally applicable to Alzheimer's: "“Much pain can be avoided with better information, empathy and planning.”¹

Definition

Alzheimer's disease (AD) is a “*progressive neurologic disease of the brain that leads to the irreversible loss of neurons and dementia.*”² AD is the most common form of dementia.³ There are no periods of remission or improvement.⁴ There is no cure.⁵

Dame Iris Murdoch, the British author, died of AD in 1999.⁶ She called it “a dark and terrible place.”⁷

Prevalence. Is prevalence increasing?

Florida had 331,387 people with Alzheimer's in 2000. The state expected to have 541,898 Alzheimer's patients in 2010 (a 60% increase) and 628,627 by 2015 (a 90% increase in 15 years).⁸

Nationwide, 10% of the people reaching age 65 have AD. That rises to 50% of persons reaching age 85 and the percent climbs beyond that age.⁹ The overall number of Americans with AD doubled between 1980 and 2006.¹⁰

AD is not as common in less developed countries.¹¹

Why it is called Alzheimer's?

A German psychiatrist, Alois Alzheimer (1864-1915), named the disease after himself in 1906.¹² He had begun observing a female patient, Auguste Dieter, in 1901, who was institutionalized after not being able to care for herself.¹³ Following her death, he examined her brain and noticed three abnormalities.¹⁴ He was the first to bring together the symptoms and the physical disturbances in the brain.¹⁵



Auguste Dieter, the patient whose illness led to the discovery of Alzheimer's disease

For most of the 20th century, the term AD was restricted to persons between the ages of 45 to 65 who had symptoms of dementia.¹⁶ Today the name is used with no restrictions as to age.¹⁷

Does Alzheimer's disease just mean dementia?

No. Although AD is the most common form of dementia, there are other types, for example: vascular dementia and that arising from Parkinson's disease, Huntington's disease, AIDS, and alcoholism.¹⁸

Symptoms or characteristics of AD

The Alzheimer's Association lists 10 warning signs of AD:¹⁹

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

There are 4 stages to AD.

Pre-dementia

Symptoms may occur up to 8 years before a diagnosis of AD can be established.²⁰ Behaviors put down to age may actually be early symptoms of AD.²¹

- Memory loss—trouble remembering recently learned things, inability to learn new things²²
- Problems with attention, planning, flexibility, abstract thinking²³
- Apathy²⁴

Early Dementia²⁵

- Increasing memory and learning problems
- Shrinking vocabulary and word fluency but still able to express basic ideas
- Difficulty concentrating²⁶
- Avoiding new situations²⁷
- Some impairment of fine motor tasks

Moderate Dementia²⁸

- Inability to live independently
- Choosing wrong words
- Loses ability to read or write
- Complex motor skills deteriorate
- Long term memory damaged
- Wandering
- Aggression
- Urinary incontinence
- Sundowning²⁹

Advanced Dementia³⁰

- Complete dependence on caregivers
- Speech eventually completely lost
- Extreme apathy
- Minimal emotional response³¹
- Walk with shuffle³²
- Unable to recognize “familiar objects or people”³³
- Exhaustion
- Loss of muscle mass
- Loss of mobility
- Inability to feed themselves
- Death (from other causes)³⁴

Physically, AD occurs when neurons and synapses in the cerebral cortex and certain subcortical regions are lost, causing those and other parts of the brain to begin shutting down.³⁵

Diagnosis³⁶

The only way to be certain a person has AD is to examine the brain tissue post-mortem. However, a thorough assessment can be almost 90% accurate. The assessment looks for other causes (besides AD) to explain the problems. It may involve 3 areas:

- Physical exam (including blood work, X rays, CAT scans, hearing and vision exams). SPECT (single photon emission computed tomography) appears

particularly good at distinguishing AD from other causes in people who already have dementia.³⁷

- Family interviews (including the history of the problems and a family and medical history). Part of the reason for this is that the patient is often unaware of deterioration.³⁸
- Mental status tests (including cognitive—such as the Mini Mental State Examination (MMSE) and the Blessed Dementia Rating Scale—and psychological exams)

New diagnostic approaches include analyzing cerebrospinal fluid for amyloid beta or tau proteins³⁹ and PIB PET which images beta-amyloid deposits. As a predictor, PIB PET is reported to be 86% accurate in determining which persons will develop AD within 2 years and 92% accurate in eliminating the possibility of developing AD in the future.⁴⁰

Causes

No one knows. There are 3 hypotheses.

- Cholinergic hypothesis suggests reduced synthesis of the neurotransmitter acetylcholine causes AD.⁴¹ However, drugs supplementing acetylcholine have not been very effective against AD.
- The amyloid hypothesis (1991) thinks amyloid beta deposits cause AD.⁴² The major genetic risk factor for AD sees excessive amyloid beta build up

before AD begins.⁴³ A vaccine in early human trials which cleared amyloid beta deposits did not effect AD.⁴⁴

- The tau hypothesis blames tau protein abnormalities for AD.⁴⁵

Genetics are not believed to be a major factor in developing the disease, though some genes may increase the risk.⁴⁶

As noted above, AD is, in a sense, a disease of civilization. It occurs less frequently in less developed countries.⁴⁷ This might be a coincidence or there might be a difference between where AD does occur and where it doesn't that is responsible for the disease.

Specifically, it would be interesting to compare water, food, food containers, inoculation history and previous insecticide use between the two sides to see if any correlations to the disease are suggested.

Or it might be possible that at some level of stimulation, the brain fries out. It is interesting that the prevalence of Alzheimer's in the United States is increasing as the sources of stimulation are also exploding. Though this too may be a coincidence.

Life Expectancy

The mean life expectancy following a diagnosis of AD is 7 years.⁴⁸ 97% of patients die within 14 years of diagnosis.⁴⁹

Prevention

Intellectual activity has been linked to a reduced risk for AD but why this works is unknown. Examples cited include chess, regular social interaction, reading, board games, crossword puzzles, and musical instruments.⁵⁰

Physical activity shows a similar lessened risk.⁵¹

A 21 year study showed that people who were heavy coffee drinkers at midlife (3-4 cups a day) had a 65% reduced risk of having AD.⁵²

Not smoking eliminates a significant risk factor for AD.⁵³

Famous People with AD

AD is no respecter of persons. It attacks leaders (President Ronald Reagan, died 2004,⁵⁴ and Prime Minister Harold Wilson , died 1995),⁵⁵ artists (Rita Haywood, died 1987,⁵⁶ and Charlton Heston, died 2008)⁵⁷, authors (Sir Terry Pratchett, who announced he had AD in 2007).⁵⁸

President Reagan wrote the nation a letter in 1994 about having the disease, five years after leaving the White House.⁵⁹

KEY POINTS

Chapter 1: What is Alzheimer's Disease?

Why knowledge of Alzheimer's disease is a critical skill for a profession guardian

- Understands what the ward is facing
- Knows what best care looks like

Definition

- Progressive
- Irreversible dementia

Prevalence. Is prevalence increasing?

- 50% of people reaching age 85 in the US have AD
- The number of Americans with AD is increasing

Why is it called Alzheimer's?

- Named by (or after) a German psychiatrist
- The name is not restricted by age

Does Alzheimer's disease just mean dementia?

- No
- Though it is the most common form of dementia

Symptoms or characteristics of AD

- 10 warning signs
- 4 stages

Diagnosis

- Assessment
- New diagnostic approaches

Causes

- No one knows. There are 3 hypotheses.
- Occurs less frequently in less developed countries

Life expectancy

- Mean life expectancy is 7 years
- 97% of patients die within 14 years of diagnosis

Prevention

- Intellectual activity has been linked to a reduced risk.
- So has physical activity

Chapter 2: Palliative Management

Management of AD attempts to make the patient more comfortable. There is no way at present to slow, halt or reverse the disease.

There are three management techniques. Two—pharmaceutical and psychosocial intervention—are discussed in this chapter. Caregiving is reviewed in Chapters 4 and 5.

Pharmaceutical Management

- Acetylcholinesterase inhibitors represent 3 of the 4 drugs approved by the Food and Drug Administration to “treat” AD. These three are marketed under the brand names Aricept,⁶⁰ Razadyne⁶¹ and Exelon.⁶² Only Aricept is approved for advanced AD.⁶³ These drugs do not delay the onset of AD.⁶⁴ The most common known side effects (10-20% of patients) are nausea and vomiting.⁶⁵

About half the people who take these drugs see a delay in the worsening of symptoms for six to twelve months.⁶⁶

- Memantine, a NMDA receptor antagonist marketed under 4 brand names, is used in the middle and last stages of AD.⁶⁷ Uncommon and mild side effects include hallucinations, confusion, dizziness, headache and fatigue.⁶⁸

- Anti-psychotic drugs are used to reduce aggression and psychosis in AD patients.⁶⁹ But their side effects are too great for routine use.⁷⁰ Anti-anxiety and antidepressant drugs may also be prescribed.⁷¹

Psychosocial Intervention

- Behavioral intervention asks what triggered a particular problem.⁷² Intervention may try to change the patient's response to that trigger.⁷³ While effective for some problem behaviors, as incontinence, for others it is unproven.⁷⁴
- Emotion-oriented interventions are not scientifically proven but some feel they help people in the early stages of AD to accept the illness. These may include discussing past experiences with pictures, items, music and sounds from previous times (reminiscence therapy) and playing back the recorded voices of close relatives (simulated presence therapy).⁷⁵
- Cognitive-oriented treatment may present the patient with information about time, place or person, to correct misimpressions (reality orientation) or exercise specific brain functions (cognitive retraining). The effects are short-lived and some patients become frustrated.⁷⁶ There was a move in the 1990s not to correct a patient's mistakes about time; caregivers would participate

in whatever time or situation the patient was imaging.⁷⁷

- Stimulation-oriented treatment uses recreation (art, music, pet, exercise, for example). This may improve a patient's behavior and mood.⁷⁸

KEY POINTS

Chapter 2: Palliative Management

Pharmaceutical Management

- 4 drugs

Psychosocial Intervention

- 4 approaches
- Nothing to get excited about

Chapter 3: Impact on Professional Guardianship

Creating a Guardianship

AD may be the trigger that starts the professional guardianship, a process that cost between \$3,500 and \$5,000 in 2003.⁷⁹

Any competent person in Florida may file a Petition for Incapacity to determine another person's capacity and a Petition for Appointment of Guardian.⁸⁰

The court then has 5 days to appoint a 3 person examining committee and an attorney to represent the alleged incapacitated person (AIP). (The AIP may substitute counsel of their own choosing.)⁸¹ At least one member of the committee will be a licensed physician or psychiatrist. The committee has 15 days to submit the report.⁸²

Having received the report, the court holds a hearing within 14 days. If the person is found to be incapacitated, the court looks for the least restrictive alternative to deal with the situation. Assuming assets are available, the AIP who is determined to be incapacitated may be made to pay for these proceedings.⁸³ (If the AIP is found to be OK, it is not clear who pays for the examining committee.⁸⁴ Potentially the person who brought the action could be made to pay.⁸⁵)

Incredibly, that attorney the court appointed for the AIP can waive the right to a hearing. One study reported they did so 90% of the time in Florida.⁸⁶

The committee's report can be contested by filing a motion to strike the report.⁸⁷

During this process, the judge may appoint a emergency temporary guardian (ETG) if the court thinks the AIP or AIP's property are in imminent danger and need interim protection.⁸⁸ The appointment is for 60 days (which may be extended indefinitely by the court) or until a permanent guardian is appointed.⁸⁹

There can be competing petitions to appoint a guardian. In *Butler vs. Peacock*, the AIP's choice for guardian, Butler, filed a petition. So did Wood.⁹⁰

If the court chooses a guardianship, the AIP becomes a ward. The court may set up a plenary (full) guardianship or limit the guardian's powers for a ward who still retains some capacity.⁹¹

The finding of the court can be appealed.⁹²

Alternatives to Guardianship

It is suggested there are numerous ways an incapacitated person can avoid a professional guardianship by preplanning.⁹³

- Durable power of attorney

- Designating a health care surrogate
- Jointly holding assets
- Guardian Advocate for Developmentally Disabled
- Guardian Advocate for Mental Health Decisions
- Living Trust
- Appointing a guardian prior to need (and before incapacitation)
- Health Care Surrogate. Appointed prior to need by the ward. Can survive the guardianship but may also be limited or revoked by the court.⁹⁴
- Non-professional guardian
- Public guardian

However, preplanning may turn out to be useless. In her will, Mallie Peacock designated Joyce Butler to be her guardian. The court appointed someone else.⁹⁵

Carol Kinnear updated her trust to say she wanted to remain in her home. The court appointed a non-family guardian who removed her to an allegedly secret location.⁹⁶

Ward's Preferences

A *Model Code of Ethics for Guardians* has a 5 part test for the guardian decision-making on behalf of the ward. The first test is what does the ward prefer? In Florida, for example, if the ward is over the age of 14, the guardian “*shall honor*” the ward’s feelings about how and where to live, to the extent the ward’s resources permit.⁹⁷

A court in another state wrote, "Even though the ward is incompetent; his preference is "entitled to serious consideration."" In that case, the ward preferred not to take Stelazine, which was being used to control schizophrenia. Ultimately the judge continued the court order requiring the administration of the drug. But the decision-making process began with the ward's preference.⁹⁸

If the ward is in pre-dementia or early dementia, the guardian may be able to interview her and ask what she'd prefer on a given topic. If the ward is still living independently, there may be a slower response time than with a younger person. Here are some tips about communicating:

- Let the phone ring 15 times⁹⁹
- Wait 5 minutes after knocking on the door¹⁰⁰
- Reduce distracting noises before beginning the conversation (turn off the TV or radio, close the door)¹⁰¹ If there are many people talking in the room, it might be wise to move the interview to a quieter place.¹⁰²
- Sit down to have the conversation so you're at the same eye level as the ward.¹⁰³
- Don't jump right in. Start off casually, talking about the weather or lunch.¹⁰⁴ A friend of mine tells the story of a church where the pastor preached

poorly. The bishop—an awful person—came along and preached beautifully. But he never started off with a sermon; he told a little story first.

- A good conversation topic is grandchildren. Most grandparents proudly love to talk about their grandkids.¹⁰⁵ (Note that in the later stages of the disease they may not remember their grandchildren.)
- Memories are important. Give the ward a chance to share.¹⁰⁶
- Once you jump in, don't jump around too often. Stick with one topic for a while.¹⁰⁷
- Talk with short sentences and questions. Give the older person more time to respond than you would with one of your younger peers.¹⁰⁸
- Use plain language. Forget jargon.¹⁰⁹
- Ask for choices rather than giving open-ended questions. "Would you like this or that?" may work better than "Would you like -----?"¹¹⁰
- Speak clearly and with eye contact.¹¹¹
- Do you need to raise your volume a little bit so the ward can hear you more easily?¹¹²

- Can you use visual aids? If the ward has hearing or memory problems, maybe you can help get your point across with a picture.¹¹³
- Be respectful. There is a tendency in the young to think they know it all and that the old are falling behind. But, as Dr. Pipher writes, our elders “cope with experiences that would take down a younger person.”¹¹⁴

The people in their 80s today were children or teenagers during the Great Depression. They served in World War II or had brothers who did. Their sister or mother may have been Rosie the Riveter.¹¹⁵ They are proud to have served in World War II and the Korean War. Gold Star Mothers were honored.¹¹⁶ They were shaped by a different set of events than we.

They may have a different language and worldview.¹¹⁷ Of course, there is always the exception but generally talking to a person in their 80s requires a different technique than to talking to a friend of the guardian's age.

A guardian who grew up in the 1950s was perhaps more speculative of war. Coffins which were illegal to photograph in the early 2000s represent a far different perspective than that current in the Second World War.

The ward who grew up in the United States is perhaps still coming from “another country” than the guardian, who needs to be sensitive to this in order to communicate well.

It is undoubtedly the preference of the ward to remain at home. This may not be possible, particularly in moderate and advanced dementia.

The ward's preference is not all conclusive—it is balanced against the other 4 elements of the *Model Code's* chain: substantial harm, best interest, independent opinion and knowledge.¹¹⁸ But the inquiry always starts there—what does the ward want? The ward is a person and not a tally on a checklist. The guardianship aspires to be not an autocratic paternalistic procedure but, to the extent possible, a collaboration.

The time will come, though, in later stages of AD, when the ward will be unable to communicate preferences. The guardian then looks to the ward's historical lifestyle and last known values to determine preferences.¹¹⁹

Once institutionalization occurs, the possible range of preferences will diminish. Considering preferences though will guard against the danger of infantilizing the ward or, to put it more bluntly, will avoid ward warehousing.

Given the lack of communication, the guardian may consider visiting the ward to be a waste of time. A quarterly visit, however, is required by Florida law.¹²⁰ One judge recommends a monthly meeting.¹²¹

Visits serve a dual purpose so are worthwhile even if no meaningful communication is possible with the ward.

The guardian is monitoring the level of care. Criteria—things to look for—are discussed in Chapters 4 and 5. For this reason, at least some visits ought to be unannounced.

In the real world, are ward's preferences actually considered? In one Florida case, the guardian is alleged to have removed the wealthy ward from her home despite her written desire to remain there and blocked any communication from the family, not even telling them where the ward is.

Besides being ethically required, considering what a ward would want forces the guardian to humanize the ward and is good public relations with the family. It might even keep your name out of the newspapers.

Enhancing the Ward's Independence

The guardian's relationship with the ward is like a three tier wedding cake, the bottom layer being enhance. The guardian is always striving to enhance the ward's independence. Again and again in specific discussions—in housing, care, and estate—"least restrictive" is used to describe what the guardian should achieve for the ward.¹²²

Unfortunately this principle is of little use in the AD setting. If the guardianship begins early enough, the guardian may be able to afford the ward a remnant of independent living. But inexorably the illness' decline will lead to institutionalization.

Then the guardian's role becomes to afford the ward the dignity and comfort the ward can no longer attain for herself or himself. Hence the emphasis moves to protection.

Protecting the Ward

Protection is the major task of the guardian in the Alzheimer's setting. The guardian safeguards the health and well being of the ward,¹²³ defending "against abuse, neglect and exploitation."¹²⁴

The ward's estate, as well as person, is protected. The estate is administered "only for the benefit of the ward."¹²⁵

Protected from who?

The word creates an adversarial relationship. Me good, you bad. A more appropriate concept might be collaboration.

The guardian wants to have an effective collaboration with other stakeholders to produce a life which is safe and as interesting as possible for the ward. The two major stakeholders in the AD scenario are probably the family and the caregivers.

If one believes the stories in the paper and on the Net, families seem to get short shrift with guardians. But it makes sense for the guardian to develop as good a

relationship as possible with the family. The single most likely party to sue the guardian for a misunderstanding is the family. Who needs that kind of trouble?

A guardian can be proactive with the family. Invite them to patient care conferences. One source says less than 10% of these are attended by any family member.¹²⁶ Possibly this is a way to include them and let them see what the real issues are.

Lee Iacocca tried something similar when he saved Chrysler. He added the union director to the board of directors—the first time that happened in U.S. corporate history.¹²⁷ One of his hopes was the union would see how tough things were from the company's perspective.

[The Where to Live Decision](#)

The guardian listens to independent opinions from the ward's doctor and specialists, weighs the ward's preference (to stay home), considers the least restrictive alternative, and hears the family. At the end of the day, the ward with AD is most likely going to a facility geared to patients with the illness.

When the guardian decides to remove the ward from the ward's home, the *Model Code* suggests a third party review of that decision prior to the move, even when such precaution is not required by law.¹²⁸ Similarly, the decision to place the ward in an institution providing only custodial care should be reviewed by a third party, the *Model Code* says.¹²⁹

In Florida, moving the ward further than the adjacent county requires court approval.¹³⁰ If the move is just to the next county over, the court must be notified and advised of the compelling reason for the change.¹³¹

The question becomes not “where to live” but “which facility is best qualified.” Are the staff Certified Dementia Practitioners or Certified Dementia Care Managers vetted by the National Council of Certified Dementia Practitioners (NCCDP)?¹³²

The NCCDP, established in 2001, has standards for certification (though no examination) and continuing education requirements for re-certification.

What to expect from a facility is discussed in Chapters 4 and 5. Whether a facility under consideration operates to these standards will be a key question.

Judge Alley provides an excellent list¹³³ of criteria for how to choose a facility in her *Florida Guardianship Law and Information* (2007), which is adapted here:

- Is the facility currently licensed by the state?
- Are they rated standard or superior?
- Do they take Medicare, Medicaid, Veterans, Optional State Supplement?
- What special services do they provide? (therapy, dietician, religious services)

- Is it reasonably close to the ward's physician?
- Is it close to a hospital?
- Is it reasonably close to family, relatives and friends?
- Are the rooms clean, attractive and big enough?
- Is the facility free of unpleasant odors?
- Are the dining room and lounge clean and inviting?
- Is the food attractively served? Hot? Tasty?
- Are meal trays sitting around untouched?
- Will someone help those who cannot feed themselves?
- Are recreational and social opportunities available?
- Do the shower and bathroom have support bars?
- Are other medical professionals, such as dentist, podiatrist, optometrist available?
- Are there enough staff on duty and are they trained?

- Is the schedule of activities posted?
- Are residents encouraged (but not forced) to participate in activities?
- Are barber and beautician services available?
- Is laundry service available? Is there an extra charge? Is clothing marked?
- Are residents' belongings and clothing secure?
- Can residents decorate their own rooms? Have their own furnishings?
- Does staff respond to residents quickly and courteously?
- Is the staff fluent in the languages residents speak?
- Does the facility have mechanisms in place to help the staff cope with the pressures of being AD caregivers?¹³⁴
- Do the residents look comfortable and happy?
- Are they up and dressed by a reasonable time?
- Are they clean?
- Are their nails and hair groomed?

- Are visiting hours convenient for the resident, relatives and the guardian?
- Is there a deposit required? What are the financial arrangements? Contract terms? Extra charges?
- What is the refund policy? Bed-hold policy?
- Does the DCF or long-term Ombudsman received any complaints about the facility?
- Are deficiency reports displayed? Have they been corrected?
- Is the staff cooperative and helpful in answering these questions?
- Is the guardian allowed to come unannounced and to check the facility without a guide before committing?
- How does the facility handle end of life, if at all?
- How does the facility handle feeding interventions, such as artificial nutrition?
- Are residents required to hire personal care assistants as they lose cognitive function?
- Does the facility work with local hospice agencies, if the law allows?

- Is palliative care (designed to reduce severity of symptoms) offered when residents are dying?

How the guardian interacts with the AD care facility

The formal part of the guardian's interaction with the AD care facility is the treatment care plan.

The treatment care plan is initially formulated on the basis of the examining committee's report(s).¹³⁵ The guardian may find it useful to seek the advice of other professionals and the input of the caregivers.

The plan is part of the initial guardianship report which is filed with the court within 60 days of the guardian's appointment.¹³⁶ A new plan, including the written report of the annual physician's examination of the ward, is filed each year thereafter.¹³⁷

Any person (this includes the ward) may file an objection to the annual report within 30 days of that report being filed.¹³⁸ The court will schedule a hearing within 30 days of the objection being filed.¹³⁹

Eventually the court will issue an order approving or disapproving the report.¹⁴⁰ If the court finds any of the following, it may hold a hearing and amend the plan or enter any other order necessary to protect the ward:

- The condition of the ward requires further examination
- Any change in the proposed care, maintenance, or treatment is needed
- The ward is qualified for restoration of some or all rights
- The condition or maintenance of the ward requires the performance or doing of any other thing for the best interest of the ward which is not indicated in the plan
- There is any other matter necessary to protect the interests of the ward¹⁴¹

The treatment care plan might contain¹⁴²

- Present status of the ward (mental, medical, social, personal)
- Problems and needs of the ward
- Specific actions to address the problems/needs. Is the housing choice permanent or could less restrictive choices be made if certain conditions occur?
- Who will be performing the specific actions
- Monthly documentation of the status of the specific actions
- Likely areas for restoration of legal capacity (if any)

- A statement confirming the ward's agreement with and participation in the plan (to the extent possible)
- The doctor's written report

The plan in subsequent years should be supported by detailed progress notes. These should document any contact with any person regarding the ward, including but not limited to the ward, caregivers, and medical and court personnel. All significant events should be recorded.

These notes are not included in the annual report but are available to support the report's conclusions.

They may contain¹⁴³

- Date of contact
- Time of contact
- Length of contact
- Participants
- Issue
- Outcome
- Dated and signed by guardian

The progress notes are the concrete expression of the guardian's second major interaction with the caregiver: monitoring. This includes:¹⁴⁴

- Communicating with the ward

- Surprise Visits. Is the plan working? Is the ward clean, neat, reasonably happy? Is there any scurrying when the guardian makes a surprise visit or is there nothing to hide?
- Conferences with the caregivers, doctors and other service providers.
- Examining the charts, notes and records others keep regarding the ward

As mentioned earlier, it is useful (though not required) to invite family input in the plan and even in the conferences. Their better knowledge of the ward may produce good insights. Their participation will perhaps give them a better sense of the process and forestall misunderstandings and problems.

The Alzheimer's Association's standard of care for the disease consider the involvement of the family essential.¹⁴⁵

It may be necessary to educate facility staff regarding the role of the guardian. The Alzheimer's Association's guidelines for such facilities say "While residents possess the capacity for decision making, they have the legal right to review and revise their advance directive."¹⁴⁶

In the guardian-ward situation, a judge has determined that the ward has no capacity for decision making. Facility staff needs to realize that whether "capacity" exists or not may have been determinate conclusively by someone else.

5 Common Tasks for the Dying

Dr. Pipher reports hospice workers have found the dying must say these 5 things,¹⁴⁷ presumably to die with a feeling of peace:

- I forgive you.
- Please forgive me.
- Thank you.
- I love you.
- Good bye.

I had a friend who was somewhat astonished when the hospice worker (arriving in at 2 AM in response to a call, in robe) told the family to say “Good bye” over and over again to his comatose mother-in-law.

In AD the interval between being able to express these ideas and death can be very wide—years. The guardian may wish to discuss these sentiments with the ward before advanced dementia arrives.

KEY POINTS

Chapter 3: Impact on Professional Guardianship

Creating a Guardianship

- A petition for incapacity is filed.
- The court appoints a committee to examine the AIP.

Alternatives to Guardianship

- Several options
- Effectiveness iffy

Ward's Preferences

- Entitled to serious consideration even when the ward is incompetent
- Communicating with AD patients is made easier with specific skills.

Enhancing the Ward's Independence

- Inexorably the disease's decline leads to institutionalization.

Protecting the Ward

- Major task
- Collaboration with other stakeholders

The Where to Live Decision

- AD facility probable
- How to evaluate facilities

How the guardian interacts with the AD care facility

- Treatment care plan
- Monitoring and progress notes

Chapter 4: Standard of Care for Alzheimer's Patients Prior to End of Life¹⁴⁸

The Alzheimer's Association funded a 3 year study and conducted a "comprehensive literature review" to develop the *Dementia Care Practice Recommendations*. They state that 26 organizations support and accept Phase 1 of the Recommendations,¹⁴⁹ with 24 expressing the same for Phase 2 and 31 for Phase 3.

The guardian with an AD ward is encouraged to read the *Recommendations* in full. They are available online at

http://www.alz.org/national/documents/brochure_DC_PRphases1n2.pdf (Phases 1 and 2; 32 pages) and http://www.alz.org/national/documents/brochure_DC_PRphase3.pdf (Phase 3; 28 pages).

Dementia Care: Initial Considerations

Each resident is an unique individual still capable of experiencing "joy, comfort, meaning, and growth in their lives."

The best care comes from a community where there are quality relationships between staff, resident, family and significant others.

The foundation of the approach is a “holistic”¹⁵⁰ assessment of the resident’s abilities and care, including:

- Cognitive health
- Physical health
- Physical functioning
- Behavioral status
- Sensory capabilities
- Decision-making capacity
- Communications abilities
- Personal background
- Cultural preferences
- Spiritual preferences

The primary method for doing the assessment is interviewing the resident, family and significant others. The values discovered for these items may change at different times of the day.

This assessment gives the staff a “thorough knowledge” of the resident, enabling development of “person-centered” strategies for handling change. This plan is to be created *with* the assistance of the resident.

The plan may include referrals to appropriate sources. The plan should be disseminated to all staff members caring for the resident.

The assessment / plan chain should be re-done periodically, particularly after significant changes (such as when the resident returns to the facility after a hospital stay.)

To implement the plan, staff should be empowered to make decisions at relatively low levels. This capability is supported by continuing training.

Adequate Food and Fluid Consumption

Each resident is individually assessed (including weight) so a plan can be developed to solve issues.

Reasons a resident might be eating less than adequately include:

- No longer recognizing hunger or thirst
- Reduced smell or taste
- Difficulty swallowing
- Difficulty recognizing utensils or feeding self
- Depression
- Physiological or behavioral conditions
- Difficulty with balance, coordination, strength or endurance
- End of life

Again, residents can be involved in the plans, perhaps by helping plan menus or time of meals. Slow eaters may need extra time to finish.

Limited mealtime distractions and heightened visual contrast between plate, food and place setting can help increase attention on the food.

Mealtimes are good opportunities for staff to sit down, interact with residents and check for changes in the

assessment. 25% of a meal being left on a plate is a concern. Does it mean Mr. Brown doesn't like liver and onions (who does?) or that help with a new issue is needed?

Fluids throughout the day should be encouraged.

Pain Management

Pain is an individual experience. Poorly managed pain leads to behavioral symptoms and unnecessary drugs.

Routine pain assessment should include

- Site of pain
- Type of pain
- Effect of pain on person
- What triggers the pain?
- In the pain acute or chronic?
- Good and bad sides of treatment

Staff ought to observe the resident while moving as well as at rest, particularly looking for clues to unremarked pain, such as grimaces. *All* staff should engage in pain assessment—recording observations and reporting them to nursing staff.

Prevention of pain includes avoiding the causes and, if necessary, regular medication.

Social Engagement and Involvement in Meaningful Activities

Activities maintain and enhance an individual's dignity. Best practice is to offer lots of opportunities to interact **with** (not "to" or "for") the resident. These go from brief, meaningful encounters with staff to more formal planned activities.

Gear the activities to the resident by assessing

- Capacity for physical movement
- Capacity for mental stimulation
- Interest in social integration (respect preference for solitude)
- Desire for spiritual participation
- Cultural values
- Specific recreational interests and preferences

Activities engage residents and encourage use of remaining skills and independence. This is better than residents simply watching something happen. The outcome is not as important as the process. Frequent activities are better than few. The attention span for a task is 30 minutes or less so plan formal activities accordingly.

Activities can involve families. *Another Country* cites examples where co-mingling of the generations into a community at a facility overcomes younger people's xenophobia of the old.¹⁵¹

Resident Wandering

The perception that resident wandering (RW) is bad is not necessarily correct. There are good things which happen from RW:

- Stimulates social contact
- Maintains mobility
- Preserves strength
- Prevents skin breakdown and constipation
- Enhances mood

The facility can provide opportunities for walking, including food, drinks and a companion for a resident “on the go.”

RW often has a reason. This should be assessed and addressed. What is the resident trying to say by wandering? Possible causes:

- Physical need
- Social needs
- Present place is irritating so let's move somewhere else
- Distress due to changes
- Pain
- Depression
- Delusion
- Stimulation

Still, in some instances RW is inappropriate, as when it results in the resident attempting to leave the facility or invading someone else's privacy.

Successful exit seeking is called elopement. 45% of elopement occurs within the first 48 hours after admission. This is a clue to develop ceremonies and procedures welcoming the resident. (On the other hand, it makes one wonder why it's so appalling easy for residents inexperienced with these facilities to get out.)

80% of elopements come from persistent wanderers. (Since nearly half of successful exits occur within 2 days of admission, the term "persistent wanderer" must refer to a resident's overall RW career spanning more than one facility.) It is therefore relatively easy to distribute photographs of persistent wanderers (high risk escape artists) to staff to be especially careful about.

The design of a facility can also discourage elopement. Reduce visual clue to exits, to the extent the law allows. Avoid windows in or beside doors.

Resident Falls

Resident movement is important. But, perhaps counter-intuitively, immobility increases the risk of falls.

The old are more at risk from falls than the young—breaks are more debilitating in the old and may create fear that lessens mobility ("I don't want to fall again.")

Assessment of fall history when the resident enters is important. Closely watching the new resident for the first 48 hours when the facility is unfamiliar helps prevent

falls. Each fall should generate an assessment—why did it happen? What do we do about it?

There are individual risk factors and environmental risk conditions which contribute to falls. Minimizing these factors and conditions can reduce resident falls.

Individual risk factors:

- Depression
- Fatigue
- History of falls
- Postural hypotension
- Incontinence
- Prolonged immobility
- Medication
- Visual impairment
- Improper footwear
- Forgetting to use assistive devices (such as walker)

Environmental risk conditions:

- Confusing environment
- Clutter
- Unclear path to bathroom
- Inadequate cueing
- Unstable furniture
- Lack of handrails
- Floors or ground that are uneven, slippery or have glare
- Inadequate lighting
- Weather conditions

- Toilet and sink that visually blend into the wall and floor

Physical Restraint-Free Care

Physical restraints harm normal functioning, contribute to de-conditioning and have emotional consequences. They negate individualized care; they block seeing the resident as a person.

Except in medical emergencies, physical restraints have no place in modern AD care. When they are used under a physician's orders, the guardian needs to be notified as soon as possible.

Physical restraints include situations where the resident cannot exit without assistance, such as

- Side rails on beds
- Over-the-bed tables and trays that cannot be removed without assistance
- Chairs or recliners which cannot be exited without help

KEY POINTS

Chapter 4: Standard of Care for Alzheimer's Patients Prior to End of Life

Dementia Care: Initial Considerations

- Each patient is still an individual capable of feeling.
- A thorough assessment is fundamental.

Adequate Food and Fluid Consumption

- Each resident is individually assessed.
- Residents can help plan menus and meal schedules.

Pain Management

- Poorly managed pain can lead to unnecessary medications.
- All staff should continually assess for pain.

Social Engagement and Involvement in Meaningful Activities

- Activities maintain and enhance an individual's dignity.
- Frequent activities engaging residents and using remaining skills and independence are key.

Resident Wandering

- Can be a good thing. May be a clue to problems.
- In some instance, it is inappropriate, as in elopement or invading another's privacy

Resident Falls

- Assess and minimize individual risk factors
- Assess and minimize environmental risk conditions

Physical Restraint-Free Care

- Physical restraints are inappropriate except when ordered by a physician in a medical emergency.
- Chairs residents cannot exit without help are physical restraints.

Chapter 5: Standard of Care for Alzheimer's Patients At End of Life¹⁵²

Communication with residents and family

Discuss preferences with the ward as early as possible, in other words while the ward still can.

Communication begins when selecting a facility (see also Chapter 3)—end of life discussions should begin at admission. About 2/3 of dementia-related deaths occur in nursing homes.

How does the facility handle end of life, if at all?

- How does the facility handle feeding interventions, such as artificial nutrition?
- Are residents required to hire personal care assistants as they lose cognitive function?
- Does the facility work with local hospice agencies, if the law allows?
- Is palliative care (designed to reduce severity of symptoms) offered when residents are dying?

Communication continues with regularly scheduled meetings involving the ward, guardian, family, facility staff, other care team (including physician), and hospice nurse or coordinator (if hospice is being used). These meetings can occur in person or by telephone conference.

Decision Making

The guardian should supply the facility with the letter of guardianship.

The facility should be a source of information on end of life issues and options.

Decisions to be discussed in the regular meetings mentioned in the previous section (but ultimately to be made by the guardian) include

- Cardiopulmonary resuscitation
- Invasive medical procedures (surgery, blood tests, dialysis)
- Hospitalization
- Intensive Care Units
- Ventilators
- Artificial nutrition/hydration
- Antibiotics
- Preventative health screening, medication, dietary restrictions

The guardian requires court approval for experimental procedures or to terminate life support.¹⁵³

Review care decisions and goals regularly. Appropriate team members should translate decisions and goals into medical orders.

Hospice

If hospice is used, hospice communicates with the facility regarding care. The two of them decide which staff (hospice or facility) will be the family's primary contact.

The hospice and facility may need to educate each other on what they do and their capabilities.

Assessment and Care for Physical Symptoms Including Pain

Preemptive care (good dental hygiene, for example) can prevent pain.

All staff (including direct care staff) should assess for pain and report to supervisors as necessary. Ask the family how the resident communicates pain. Keeping the same staff assigned to a particular resident may make pain recognition easier.

At end of life, AD patients are unable to speak understandably. So staff must detect pain in other ways.

Signs of pain:

- Changes in behavior (more withdrawn or agitated)
- Changes in mental status (more confusion or less responsiveness)
- Verbal communication (yelling, calling out)

- Motor restlessness
- Facial grimace
- Teeth grinding
- Gestures
- Rigidity of posture or position
- Labored breathing pattern
- Changes in ability to swallow
- Loss of appetite or thirst
- Very thirsty
- Disturbed or restless sleep
- Scratching or picking at skins/other body parts
- Changes in skin condition
- Excessive sweating
- Dry mouth
- Drooling
- Accumulation of secretions (eye, nose, lungs, genitalia)
- Bowel movements or incontinence
- Change in general cleanliness
- Change in grooming habits

Assessment and Care for Behavioral Symptoms

A resident may indicate distress through a behavioral symptom.

Behavior should be tolerated unless it is distressing or a potential risk to the resident or others.

Staff should take the signal and try to solve the problem. Medicating for docility without finding the cause of the behavior is inappropriate.

As always, direct care staff, the front line, needs to be trained for behavioral symptoms, which include

- Changes in attention span
- Psychomotor agitation
- Changes in mood (depressed, anxious, fearful)
- Hallucinations (visual, auditory, tactile)
- Withdrawal from others
- Groaning or calling out
- Facial grimacing
- Striking out or other physical gestures of discomfort or distress

Psychosocial and Spiritual Support of Residents

Positive interactions probably benefit a resident, though the resident cannot respond to them.

The support team should support the guardian and family as well as the resident. They should communicate the symptoms of dying, including

- Decreased need for food and drink because body functions are gradually shutting down.
- Difficulty swallowing. The mouth will become drier and needs to be moistened.
- Increased sleeping and more difficulty in waking up.
- Increased restlessness.
- Decreased urine output as kidneys slow down.
- Breathing may sound moist because of relaxed vocal cords and a small amount of oral secretions collecting at back of throat.

- Change in breathing patterns, with 10-30 second periods of no breathing, referred to as apnea.
- Moaning sounds, which may not necessarily signify pain.
- Arms and legs may become cool to the touch and bluish in color. There also may be mottling (reddish blue blotches) on the underside of the hands and feet. The underside of the body may be somewhat darker in color. These physical signs are a result of the slowing down of blood circulation and do not necessarily indicate that the person is too cold.
- Fevers may occur.

What happens after death should be clearly communicated to the guardian and family, such as

- Who will be called first
- What happens to the body
- When the ward may remove the resident's belongings

Family Participation in Resident's End-of-Life Care

Family can interact with the resident:

- Playing favorite music
- Reading aloud from a favorite book
- Holding hands
- Showing pictures or photographs
- Speaking soothingly

The facility can support the family by:

- Encouraging use of a refrigerator
- Providing snacks
- Offering a private room when death is near
- Putting a symbol (such as a flower) outside the room when death is near to encourage staff in the area to be as quiet as possible
- To be accessible for questions even if not physically present by phone or email

Acknowledgement of Death and Bereavement Services

The facility should acknowledge the death. Here are some possible ways to do this:

- Alert staff members so no one walks in unaware
- Tell the roommate
- Not re-use the room or bed for a period of time
- Place a flower on the bed for a period of time
- Bedside ceremony
- Condolence card to family
- Express concern by phone
- In house memorial service. Allows staff and residences to grieve.
- Provide memorial book for community to fill in (with family permission)
- Provide residents with transportation to the funeral
- Send a representative to the funeral (This is not in the Alzheimer's Association's *Recommendations* but wouldn't it say something about the facility and comfort the family?)

KEY POINTS

Chapter 5: Standard of Care for Alzheimer's Patients at End of Life

Communication with residents and family

- About 2/3 of dementia-related deaths occur in nursing homes.
- How a facility handles End of Life is a part of the selection process.

Decision Making

- Give the facility a copy of the letter of guardianship.
- The guardian consults with the ward, family, facility staff and other care team but the guardian makes the decision.

Hospice

- The hospice and facility need to sit down and define roles.
- They may need to educate each other about what each can do.

Assessment and Care for Physical Symptoms Including Pain

- All staff (especially direct care staff) should continually monitor residents for pain.

- End of Life AD patients are unable to communicate verbally so staff need to know the signs of pain.

Assessment and Care for Behavioral Symptoms

- Behavioral symptoms may signal a problem which needs help.
- As always, direct care staff need to be trained to spot.

Psychosocial and Spiritual Support of Residents

- Staff should tell family about the symptoms of dying.
- There should be no secrets about what happens after the resident dies.

Family Participation in Resident's End of Life Care

- Family can interact with the resident.
- The facility can ease the family's last days with the resident in a myriad of ways.

Acknowledgement of Death and Bereavement Services

- The facility should be respectful of the family's sensibilities.
- The facility has a responsibility to help staff and other residents in the grieving process.

Appendices

What is Hospice?

(from the National Cancer Institute)

Hospice is a concept of care that involves health professionals and volunteers who provide medical, psychological, and spiritual support to terminally ill patients and their loved ones. Hospice stresses quality of life—peace, comfort, and dignity.

A principal aim of hospice is to control pain and other symptoms so the patient can remain as alert and comfortable as possible. Hospice services are available to persons who can no longer benefit from curative treatment; the typical hospice patient has a life expectancy of 6 months or less.

Hospice programs provide services in various settings: the home, hospice centers, hospitals, or skilled nursing facilities. Patients' families are also an important focus of hospice care, and services are designed to provide them with the assistance and support they need.

The following resources may offer assistance for people seeking hospice care and information:

- The **National Hospice and Palliative Care Organization** (NHPCO) is a membership organization representing programs and professionals that provide hospice and palliative care in the United States. NHPCO's mission is to

lead and mobilize social change for improved care at the end of life. NHPCO offers publications, information about how to find a hospice, and information about the financial aspects of hospice. Some Spanish-language publications are available, and staff are able to answer calls in Spanish.

Address: Suite 625
1700 Diagonal Road
Alexandria, VA 22314
Telephone: 703-837-1500
1-800-658-8898 (helpline)
E-mail: nhpco_info@nhpco.org
Web site: <http://www.nhpco.org/templates/1/homepage.cfm>

- The **Hospice Association of America** (HAA) is an advocate for hospice organizations. It serves hospices that are freestanding and community-based, as well as those affiliated with home care agencies and hospitals. HAA also distributes a number of publications about hospice to consumers. Publications can be viewed by accessing the organization's Web site. Topics include information about the history of hospice, the benefits of choosing a hospice program, hospice-related statistics, and locations of hospice organizations.

Address: 228 Seventh Street, SE.
Washington, DC 20003
Telephone: 202-546-4759
Web site: <http://www.nahc.org/HAA/home.html>

- The **Hospice Education Institute** serves a wide range of individuals and organizations interested in

improving and expanding hospice and palliative care throughout the United States and around the world. The Institute works to inform, educate, and support people seeking or providing care for the dying and the bereaved. HOSPICELINK, a service of the Institute, maintains a computerized database and up-to-date directory of all hospice and palliative care programs in the United States. HOSPICELINK helps patients and their families find hospice and palliative care programs, and provides general information about the principles and practices of good hospice and palliative care.

Address: 3 Unity Square
Post Office Box 98
Machiasport, ME 04655-0098

Telephone: 207-255-8800
1-800-331-1620

E-mail: info@hospiceworld.org

Web site: <http://www.hospiceworld.org>

- **Hospice Net** is an organization that works exclusively through the Internet. This organization's Web site provides hospice-related information for patients, children, and caregivers. It contains articles regarding end-of-life issues and is dedicated to providing information and support to patients facing life-threatening illnesses and to their families and friends.

Address: Suite 51
401 Bowling Avenue
Nashville, TN 37205-5124

E-mail: info@hospicenet.org

Web site: <http://www.hospicenet.org>

- The **American Cancer Society** (ACS) provides free fact sheets and publications about hospice. The address of a local ACS chapter can be obtained by calling the chapter's toll-free telephone number.

Telephone: 1-800-ACS-2345 (1-800-227-2345)

Web site: <http://www.cancer.org>

For many people, some hospice expenses are paid by health insurance plans (either group policies offered by employers or individual policies). Information about the types of medical costs covered by a particular policy is available from an employee's personnel office, a hospital or hospice social worker, or an insurance company. Medical costs that are not covered by insurance are sometimes tax deductible.

Medicare, a health insurance program for the elderly or disabled that is administered by the Centers for Medicare & Medicaid Services (CMS) of the Federal Government, **provides payment for hospice care**. When a patient receives services from a Medicare-certified hospice, Medicare insurance provides substantial coverage, even for some services that would not be covered outside of a hospice program.

To find a Medicare-certified hospice program, people can ask their doctor, a state hospice organization, or the state health department. The telephone number for state hospice organizations and health departments can be found in the state government section of a local telephone directory. The Medicare hotline can answer general questions about Medicare benefits and

coverage, and can refer people to their regional home health intermediary for information about Medicare-certified hospice programs. The toll-free telephone number is 1-800-MEDICARE (1-800-633-4227); deaf and hard of hearing callers with TTY equipment can call 1-877-486-2048.

The booklet *Medicare Hospice Benefits* is the official publication for Medicare hospice benefits. This booklet, which outlines the type of hospice care that is covered under Medicare and provides detailed information about hospice coverage, is available at <http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf> on the Internet.

Medicaid, a Federal program that is part of CMS and is administered by each state, is designed for patients who need financial assistance for medical expenses. Information about coverage is available from local state welfare offices, state public health departments, state social services agencies, or the state Medicaid office. Information about specific state locations may also be found at <http://cms.hhs.gov/medicaid> on the Internet.

In addition, local civic, charitable, or religious organizations may be able to help patients and their families with hospice expenses.

More Information

On Florida Guardianships

Florida Guardianship Law and Information, Hon. Nancy Alley et al, (Eighteenth Judicial Circuit, 2007)
http://www.flcourts18.org/PDF/gurardianship_rev1-07.pdf

On Alzheimer's disease

Alzheimer's Association

225 N. Michigan Avenue, Floor 17
Chicago, IL 60601-7633
800-272-3900 (toll-free)
866-403-3073 (TDD/toll-free)
www.alz.org

Alzheimer's Disease Education and Referral Center

National Institutes of Health 800 438-4380
<http://www.nia.nih.gov/alzheimers>

Alzheimer's Foundation of America

322 Eighth Avenue, 7th Floor
New York, NY 10001
866-AFA-8484 (866-232-8484; toll-free)
www.alzfdn.org

Eldercare Locator

800-677-1116 (toll-free)
www.eldercare.gov

National Institute on Aging

<http://nihseniorhealth.gov/alzheimersdisease/toc.html>

Florida Alzheimer's disease resources

Alzheimer Resource Center

1506 Lake Highland Dr. Orlando, FL 32803

Voice: (407) 843-1910 or (800) 330-1910

Fax: (407) 381-4155

<http://www.alzheimerresourcecenter.org/>

Florida Alzheimer's Disease Research Center/Byrd Alzheimer's Institute

Huntington Potter, Ph.D., Director

Florida Alzheimer's Disease Research Center

Byrd Alzheimer's Institute

4001 East Fletcher Avenue

Tampa, FL 33613

Information Line: 1-866-700-7773 (toll free)

Director's email: hpotter@health.usf.edu

Director's Tel: 813-866-1600

Director's Fax: 813-866-1601

www.floridaadrc.org

Videos on Alzheimer's disease

HBO

<http://www.hbo.com/alzheimers/>

What to Do Next

Once you've completed this 6 hours class, just sign the confirmation and we'll e-mail your certificate. You can reach Apollo Correspondence Classes in any of the following ways:

- By e-mail: go@apollo123.com
- By phone: toll free 866 506-1999
- By mail: 21162 Banff Lane, Huntington Beach, CA 92646

Thank you for choosing Apollo for your continuing education!

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¹ Mary Pipher, Ph.D., *Another Country: The Emotional Terrain of Our Elders*, 1999 (abridged audiobook)

² Medicinenet.com, *Definition of Alzheimer's disease*, 2007, <http://www.medterms.com/script/main/art.asp?articlekey=2213>. Italics added.

³ Voice of America, *Alzheimer's Disease: Into the World's Most Common Form of Dementia*, September 14, 2009, <http://www.voanews.com/specialenglish/archive/2009-09/2009-09-14-voa2.cfm?CFID=362729113&CFTOKEN=62210259&jsessionid=0030531d92d7560aa3015c3d039393b35352>

⁴ Alzheimer's Disease Research Center, *Alzheimer's Disease and Related Disorders*, University of Washington, 2009, <http://depts.washington.edu/adrcweb/UnderstandingAD/GenInfo.shtml#tests>

⁵ Alzheimer's Association, *Treatments*, 2010, http://www.alz.org/alzheimers_disease_treatments.asp

⁶ Wikipedia, Iris Murdoch, January 24, 2010, http://en.wikipedia.org/wiki/Iris_Murdoch

⁷ Voice of America, *Alzheimer's Disease: Into the World's Most Common Form of Dementia*, September 14, 2009, <http://www.voanews.com/specialenglish/archive/2009-09/2009-09-14-voa2.cfm?CFID=362729113&CFTOKEN=62210259&jsessionid=0030531d92d7560aa3015c3d039393b35352>

⁸ Guardianship Task Force, *Preliminary Report*, 2004, p. 66

⁹ Guardianship Task Force, *Preliminary Report*, 2004, p. 65. The University of Utah says the number at age 80 is 20%: Genetic Learning Center, *What is Alzheimer's disease?*, University of Utah, 2010, <http://learn.genetics.utah.edu/content/disorders/whataregd/alzheimers/>. Another source says 42% of the US population over 84 years of age had AD in 2000: Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA (August 2003). "Alzheimer disease in the US population: prevalence estimates using the 2000 census". *Arch. Neurol.* 60 (8): 1119–22

¹⁰ Erica F. Wood, *State-Level Adult Guardianship Data*, American Bar Association Commission on Law and Aging, 2006, p. 10, http://www.ncea.aoa.gov/NCEAroot/Main_Site/pdf/publication/GuardianshipData.pdf

¹¹ Ferri CP, Prince M, Brayne C, et al. (December 2005). "Global prevalence of dementia: a Delphi consensus study" (PDF). *Lancet* 366 (9503): 2112–7.

¹² Genetic Learning Center, *What is Alzheimer's disease?*, University of Utah, 2010, <http://learn.genetics.utah.edu/content/disorders/whataregd/alzheimers/>. Who Named It?, *Alois Alzheimer*, 2010, <http://www.whonamedit.com/doctor.cfm/177.html/>. Another account states psychiatrist Dr. Kraepelin suggested the disease be named after Alzheimer in 1910: Who Named It?, *Alois Alzheimer*, 2010, <http://www.whonamedit.com/doctor.cfm/177.html/>. The National Institute on Aging says the disease

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- was “named after” Alzheimer: National Institute on Aging, *Alzheimer’s Disease Fact Sheet*, 2009, <http://www.nia.nih.gov/Alzheimers/Publications/adfact.htm>
- ¹³ Who Named It?, *Alois Alzheimer*, 2010, <http://www.whonamedit.com/doctor.cfm/177.html/>
- ¹⁴ Who Named It?, *Alois Alzheimer*, 2010, <http://www.whonamedit.com/doctor.cfm/177.html/>
- ¹⁵ Wikipedia, *Alois Alzheimer*, January 30, 2010, http://en.wikipedia.org/wiki/Alois_Alzheimer
- ¹⁶ Katzman Robert, Terry Robert D, Bick Katherine L (editors) (1978). *Alzheimer's disease: senile dementia and related disorders*, pp. 595
- ¹⁷ Boller F, Forbes MM (June 1998). "History of dementia and dementia in history: an overview". *J. Neurol. Sci.* 158 (2): 125–33; Amaducci LA, Rocca WA, Schoenberg BS (November 1986). "Origin of the distinction between Alzheimer's disease and senile dementia: how history can clarify nosology". *Neurology* 36 (11): 1497–9
- ¹⁸ Alzheimer’s Disease Research Center, *Alzheimer’s Disease and Related Disorders*, University of Washington, 2009, <http://depts.washington.edu/adrcweb/UnderstandingAD/GenInfo.shtml#kinds>
- ¹⁹ Alzheimer’s Association, *10 Signs of Alzheimer’s*, 2010, http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp
- ²⁰ Bäckman L, Jones S, Berger AK, Laukka EJ, Small BJ (Sep 2004). "Multiple cognitive deficits during the transition to Alzheimer's disease". *J Intern Med* 256 (3): 195–204
- ²¹ Waldemar G, Dubois B, Emre M, *et al.* (January 2007). "Recommendations for the diagnosis and management of Alzheimer's disease and other disorders associated with dementia: EFNS guideline". *Eur J Neurol* 14 (1): e1–26
- ²² Bäckman L, Jones S, Berger AK, Laukka EJ, Small BJ (Sep 2004). "Multiple cognitive deficits during the transition to Alzheimer's disease". *J Intern Med* 256 (3): 195–204; Arnáiz E, Almkvist O (2003). "Neuropsychological features of mild cognitive impairment and preclinical Alzheimer's disease". *Acta Neurol. Scand., Suppl.* 179: 34–41
- ²³ Bäckman L, Jones S, Berger AK, Laukka EJ, Small BJ (Sep 2004). "Multiple cognitive deficits during the transition to Alzheimer's disease". *J Intern Med* 256 (3): 195–204
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