Dementia and Wandering Behavior
Dementia and Wandering Behavior
Concern for the Lost Elder

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Contents

Foreword ix
Preface xi
Acknowledgments xiii

Part I: Introduction

Introduction 3
1 Alzheimer’s Disease and Related Dementias: An Overview 9
2 Comprehensive Review of the Literature on Wandering Behavior 28
3 The Dementia Wanderer: A Profile 52

Part II: Current Community Responses to Wandering Behavior:
What Works, What Doesn’t, and Why

Introduction 71
4 The Caregiver 73
5 Law Enforcement and Technology 95
6 Long-Term Care Providers 111
Contents

Part III: Creating a Safe Environment

Introduction 129

7 The Home: Recommendations for Family Caregivers 131

8 The Facility: Recommendations for Long-Term Care and Assisted Living Residences 141

9 The Community: Recommendations for Elder Care and Acute Care Providers 156

10 The Lifesaving Role of “First Responders:” Recommendations for Police, EMS, Fire, and Search & Rescue Personnel 166

Conclusions 186
References 193

Index 207
Foreword

Alzheimer’s is rapidly becoming the epidemic of the 21st century. Today an estimated 4 million Americans suffer from this devastating illness. And unless we find a cure, this number is expected to explode to 14 million by 2050 as the Baby Boomers come of age.

In 1999, along with my good friend Chris Smith (R-NJ), I established the bipartisan Congressional Task Force on Alzheimer’s Disease to enlist our colleagues in the battle against this epidemic. One hundred and fifty-eight members strong, the Task Force has played a key role in the increase of funding for Alzheimer’s research by over $100 million since its inception. This investment in science is crucial to finding a cure, and I have no doubt that one day children will have to look to the history books to learn about Alzheimer’s disease. But until that day arrives millions of Americans will continue to face the challenges of Alzheimer’s not only as patients, but also as family caregivers living with an immense responsibility.

Until we find a cure, this nation must continue to create and to invest in programs designed to improve the lives of those affected by this illness. One crucial and unique federal program is called Safe Return. The Safe Return Program was established nationwide to assist in the identification and timely recovery of people with Alzheimer’s and related dementias who wander and become lost. Each year, the Alzheimer’s Task Force has been successful in securing full funding for this incredibly important program.

Unless one has dealt directly with an Alzheimer’s patient, it’s difficult to imagine the day-to-day challenges associated with caring for a loved one with the disease. The stress is further amplified by the need to keep constant and vigilant watch over the ambulatory Alzheimer’s patient as the disease progresses. Public awareness of Alzheimer’s disease is crucial for a variety
of reasons—but it is perhaps most crucial in order to provide a community safety net for the Alzheimer’s patient who is lost and wandering.

In *Dementia and Wandering Behavior: Concern for the Lost Elder*, authors Nina Silverstein, Gerald Flaherty and Terri Salmons Tobin provide an excellent resource for building public awareness. This easy-to-read book offers concrete suggestions for the range of professional caregivers in community and institutional settings, for people with dementia and their families in the community, as well as for first-responders such as police and search and rescue personnel.

*Dementia and Wandering Behavior: Concern for the Lost Elder* speaks to the risks associated with wandering behavior and demonstrates that acknowledgment of these risks leads to early precautions to avoid them. This in turn can lead to reduced stress on caregivers, greater autonomy for people in the earlier stages of the disease, and increased safety for anyone with Alzheimer’s who is ambulatory. Ultimately, *Dementia and Wandering Behavior: Concern for the Lost Elder* provides invaluable information to help Alzheimer’s patients remain longer and more secure with their friends and families in the community, and more safe with their caregivers in facilities. The authors embrace the goal that we as a nation should all embrace—the goal of enhancing the quality of the lives of people with dementing illnesses like Alzheimer’s disease.

Congressional Task Force on Alzheimer’s Disease
Dementia robs the afflicted of their daily experiences and future prospects. It robs us all of their companionship and wisdom. The great burden of dementia is not from the patient’s forgetting his neighbor’s name, it’s from wandering into his neighbor’s home. Our first obligation is to protect the patient and this book provides practical advice for achieving that goal.

Alzheimer’s disease creates deficits in a variety of domains. It is not simply the loss of memory, but also of language, judgment, and spatial orientation. The mode of presentation and sequence of progression is highly idiosyncratic, but one-third to one-half of the patients have spatial orientation loss early in their illness and these patients are thought to be especially prone to wandering.

Our work at the University of Rochester, and that of our colleagues around the globe, is revealing the neural mechanisms of spatial disorientation in dementia. Alzheimer’s patients who get lost in familiar surroundings have an impaired capacity to see the patterned visual motion of optic flow. Optic flow informs us about the speed and direction of our self-movement and about the three-dimensional structure of the visual environment. Alzheimer’s patients do not get lost because they have forgotten where they are going, rather, they get lost because they cannot keep track of where they have been.

After facing the tragedy of a dementia diagnosis, these patients confront a succession of painful realizations: realizing that the lifelong habit of automobile driving must be abandoned, that routine independent excursions must be curtailed, and that an independent household can no longer be maintained. Episodes of wandering and getting lost accelerate the relentless cycle of isolation and loss of independence.

Health care professionals, caregivers, and family members struggle to keep patients safe and help them adjust. Unfortunately, appropriate responses are
commonly impeded by a failure to fully recognize current impairments and further changes on the horizon. The best way to prevent this is by understanding the disease and its consequences. That understanding can begin with this book.

This book is divided into three parts. The first part deals with defining dementia as the progressive loss of functional capacity due to neurological deficits. A review of the pertinent literature is provided that emphasizes the enormity of the problem of wandering, and its devastating consequences. The diverse manifestations of dementia, its epidemiology, and its differential diagnosis are then described. This presentation offers a framework that is helpful to the professional while providing level of detail that is suitable for those who are new to the subject.

The second part deals with community responses to wandering. The presentation of general principles is extensively illustrated by specific examples from the authors' experience and the literature. The focus on wandering allows a comprehensive description of the problem and a detailed elaboration of what various community programs and institutions can do to help. In particular, the utility of the Safe Return Program is aptly exemplified and important resources for advice and useful appliances are provided.

The third part of the book addresses the needs of a variety of individual care providers. Chapter 7, on creating a safe home environment, provides the benefits of extensive experience in a clear presentation. This chapter, and others, include a number of useful lists that concisely describe the dos and don’ts of home care. Chapters 8 and 9 describe what is needed to create a supportive living program that educates staff and protects patients. Finally, Chapter 10 provides expert advice for the many community-based professionals, from social services to law enforcement, who are often called upon to rescue the wandering elder.

Alzheimer’s disease impairs sensory processing, robbing patients of the ability to extract experience from sensation. This undermines their capacity to share in everyday life and isolates them in a world of their own. This is the world in which they wander. Until dementia can be controlled, cured, and prevented we must make every effort to bridge these worlds with compassion and knowledge. I commend the authors on this worthwhile contribution to that effort.

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Acknowledgments

We hope this book can be of some help to those who each day face the challenge of finding their way through the ordinary routines of their lives. For finding our own way to the book, and through it, we acknowledge the several million people who have Alzheimer’s disease or a related disorder, and the hundreds working in the Alzheimer’s Association’s Safe Return Program nationwide.

Many others helped. Our list is not prioritized, and we suspect we may have missed a few. We thank the caregivers who participated in both our quantitative and qualitative research efforts. In the interim between the Silverstein and Salmons study in 1996 and the Salmons study in 1999, author Salmons (now Salmons Tobin) was a “walking buddy” for the late Clayton Sibley. Insights gained through her experiences with Clayton and his wife Diane contributed greatly to her doctoral research and to the awareness we hope to generate by using parts of it here.

The Gerontology Institute and Center at the University of Massachusetts Boston supported author Silverstein’s initial exploration into this topic by providing resources under the auspices of the Elder Action-Research class of the Gerontology certificate program. UMass provided a supportive environment for Salmons Tobin, who received a graduate award while there from the Association of Gerontology in Higher Education and the AARP Andrus Foundation to support her doctoral research on wandering behavior.

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PART I

Introduction
Most of the time I forgot I had Alzheimer’s in the earliest days until I realized one morning that I could not visually map out in my mind where I was supposed to go that day and it was a place I frequented. I had a hard time coming to grips with this loss of visual memory. It was this realization that made me talk to my family and get help. I have not worried about getting lost because, since that day, I do not leave the house by myself... never. To not be able to create a map in your mind is so scary.

*Member of a support group for people with early stage dementia*

*Summer 2001*

## Introduction

For people with Alzheimer’s disease or a related dementia, wandering away from home or a care facility and becoming lost is the most life-threatening behavior associated with their illness. For family and professional caregivers, it can be the most emotionally wrenching event in their caregiving experience. And while “forgetfulness” may be the symptom which most often leads families and elder care professionals to seek a diagnosis for a loved one or client, it is the frightening experience of a wandering incident that just as often leads them to seek other helpful services (Silverstein & Salmons, 1996).

Public awareness concerning Alzheimer’s disease has increased in the past decade, but for the estimated 4 million people in the United States with Alzheimer’s or a related dementia, these services remain few and far between. Although 70 to 80% of Americans with dementia live in the community (Crosby, et al., 1993; Hall, et al., 1995), nationally less than 2% receive any supportive assistance such as homemaking, home health care, or day care (Alzheimer’s Association, 1990). The most likely reasons for the low level of supportive assistance appear to be that at-risk elders do not self-report their medical or other problems, and public resources to locate high-risk elderly or to serve people with Alzheimer’s disease and their caregivers are uniformly lacking (Raschko, 1991; Silverstein, 1984).

At least 20% of people with dementia who live in the community are living alone, with estimates reaching 44% in some geographic regions (U.S. Congress, 1990). They are our neighbors and, for those in the elder service field, our clients. And they are, by definition, at risk. People with serious memory problems who live alone and have no services are at continuous imminent risk of wandering and becoming lost (Flaherty & Raia, 1994). Their often isolated environment lends itself to the psychiatric complications
of dementia, such as hallucinations and delusions, which, in turn, are conducive to wandering. As Flaherty and Raia wrote, “If the best current, practical and humane treatment for people with dementia is the almost constant reassurance they receive from others, then people with dementia who live alone spend their lives in an unenviable place, where the real fears associated with our noisy and sometimes dangerous cities, or our isolated suburbs, are only enhanced by the effects of dementia” (p. 84).

This population constitutes what social researcher Raymond Raschko (1991) has called “a social policy time bomb.” One behavior, in particular, has alerted elder care professionals to the ticking of this time bomb—the increasingly well-documented propensity of people with dementia to wander away from home and become lost. This behavior places them at risk whether they live alone or with involved caregivers. Wandering has been cited as a major cause of hospital admission (Sanford, 1975), of serious physical risk (Silverstein & Salmons, 1996) and of death (Koester & Stooksbury, 1994).

Wandering has also been described by in-home caregivers as the least manageable (Young, 1988) and most-mentioned (Calkins & Namazi, 1991) problem they face. It is a primary factor leading to placement in a long-term care facility (Ferris, 1987). In the early and middle stages of the disease, the behavior is manifest. The Alzheimer’s Association (1998) estimates that as many as seven out of ten people with Alzheimer’s disease or a related dementia will wander from home or a care facility and become lost during the course of the disease. Many will do so repeatedly (Silverstein & Salmons, 1996). In reviewing data from law enforcement and other agencies, one search and rescue expert (Koester, 2001) estimates that more than 127,000 critical wandering incidents involving people with dementia occur each year, of which only about 34,000 are reported to police. Rowe and Glover (2001) found that less than 4% of memory-impaired adults who wander away from home are able to return unassisted, and that “individuals who have regularly taken independent walks in the community on a regular basis may, on any given day, become lost and find themselves unable to return home on their own” (p. 13).

For all involved, a wandering episode is an emotionally wrenching experience. Wandering is not just another problem associated with dementia—no caregiver, for example, will call the police for problems with incontinence. Wandering is a major hallmark of dementing illness, and as such it cannot be ignored.

The purpose of this book is to enable readers to recognize wandering behavior when it occurs, to enable them to understand that wandering is indeed a life-threatening behavior, and to respond to the oft heard comment,
“There’s nothing we can do about it.” And we include people with Alzheimer’s disease and related disorders among our readers. Particularly for people with early stage Alzheimer’s, knowledge about ways to deal with the risk of wandering and becoming lost addresses issues of autonomy, not just safety. As more people are diagnosed earlier in the disease process, autonomy and self-determination will almost certainly become larger issues for patient and caregiver alike. This is why we have looked at ways, from the Alzheimer’s Association’s Safe Return Program to emerging, high-tech personal locator technologies, which can help people with dementing illnesses remain safe and relatively independent for as long as possible.

The book is also intended to promote the largely unexplored notion that this behavior is not simply an isolated symptom of Alzheimer’s disease and other dementias, but part of a process that culminates in someone with a dementing illness becoming lost. This process involves multiple interacting factors, including biochemical changes in the brain, lifelong patterns of coping with stress, and environmental stimuli (Alzheimer’s Association, 1993). For example, our “cognitive mapping” skill is associated with the parietal lobe of the brain, which controls spatial orientation. This skill enables us to get from point A to point B and back without getting lost. The parietal, temporal and occipital lobes connect in the posterior region of the brain, and comprise the brain’s visual cortex. In studying impairment of the visual cortex in Alzheimer’s, Duffy, Tetewsky, and O’Brien (2000) identified a phenomenon they termed “motion blindness,” or the lack of motion perception. They found that people with Alzheimer’s disease experienced an impaired ability to process optic flow—that complex flow of information the eyes send to the brain as we move through our environment. People with Alzheimer’s experienced increasing difficulty determining if it is they—or the objects around them—that are moving. This offers one explanation for the disorientation that can lead a person with Alzheimer’s wandering and becoming lost, even quite early in the disease process. In fact, Rosa-Brady and Dunne (1999), in an article about visual problems in Alzheimer’s disease, report that several of the participating elders in the Duffy study who had no apparent memory loss nevertheless tested abnormally for motion blindness, and later developed probable Alzheimer’s disease. According to Rosa-Brady and Dunne, this leads Duffy to believe that “motion blindness may precede memory problems in some people with Alzheimer’s. Since motion blindness was an early indicator for Alzheimer’s in some test subjects, Duffy hopes his findings will become useful in diagnostic testing, and feels they may also be helpful in identifying people with Alzheimer’s who are at increased risk for wandering.”

But while wandering behavior has been associated with damage to the visual cortex early on in the disease process, people with dementia who
become lost may also be experiencing fear, seeking exercise or companionship, looking for a childhood home, trying to get to a former place of employment, or be driven by a number of other desires or impulses. Additionally, the home or care facility from which they disappeared may or may not constitute an emotionally secure or physically safe environment. All of these factors and more come into play when someone wanders and becomes lost. Viewed in this context, this difficult behavior can often be managed.

A full exploration of how wandering behavior relates to various occupational category within the dementia care field follows in the chapters of Part II, and in Part III we will offer specific suggestions on interventions and responses for specific professions—from community and long-term care providers to police and search and rescue personnel. In Part II we will also discuss wandering from home, from a day or long-term care facility, whether by foot, by car, or by other means. Information will be categorized in such a way as to make it easily accessible for the sometimes different but always related purposes of the various professions. We hope to make this a practical, efficient, expedient resource, a sort of quick-reference book on wandering behavior for professionals across the elder care field. Part I, on the other hand, consists largely of the kinds of background information we thought necessary to illuminate the core problem of wandering and becoming lost. This information may also be useful to researchers, faculty, and students in age-related disciplines. In chapter 1, for example, the literature review provides a broad but easy to digest overview of Alzheimer’s disease and the related dementias. Such a general look at dementia will aid in our understanding of one of the most common behaviors associated with it. In chapter 2, following a full review of the research literature, we will come to a working definition of wandering behavior. Chapter 3 profiles the dementia wanderer, and offers insights drawn not only from the work of researchers, but from the immediacy of the experiences of family caregivers. In Part II, chapter 4 details some current community responses to wandering behavior, with a special focus on the Alzheimer’s Association’s national Safe Return program.

Our literature review in chapter 2 produced some useful definitions which fit particular research parameters for particular studies. Further research will no doubt focus in other ways on other aspects of the behavior. Our purpose in revisiting these definitions was not so much to formulate a working definition of our own as it was to clarify precisely what it is about wandering behavior that in our opinion most warrants the attention of elder care professionals.

Whatever the cause, wandering requires immediate intervention. The National Institute of Nursing Research (1994) identified wandering as a top-
priority area of study. We certainly agree. Elder care providers need to address the wandering process before it creates the kinds of crises which an overburdened elder service system is not currently equipped to resolve in the safest, wisest or most humane way. Our own studies, together with our reading of the literature and direct experience in cases involving people with dementia who have wandered and become lost, have led us to the following three assumptions. They are the impetus behind this book, and guide us throughout.

- If someone with a dementia can walk, that person can wander and become missing.
- If someone with a dementia is missing, that person is lost.
- And if someone with a dementia is lost, that person is at risk of harm.
Alzheimer’s is a progressive, degenerative disease which attacks the brain and results in impaired memory, thinking, language and behavior. It is the most common cause of dementia. Dementia itself is not a specific disease, but a group of symptoms which may accompany certain diseases or physical conditions (Alzheimer’s Association, 1990). In Alzheimer’s, the symptoms of dementia include a decline in intellectual functioning so severe that people with the disease gradually lose the ability to take care of themselves without assistance. There are a number of other dementing illnesses which produce similar symptoms and the same endpoint as Alzheimer’s disease. These are referred to as the Alzheimer-related dementias, and are the focus of the section Causes of Alzheimer’s Disease, which follows. There is currently no lasting medical treatment and no cure for progressive, dementing illnesses such as Alzheimer’s disease.

The disease was first described by Dr. Alois Alzheimer in 1906, although it has been with us for centuries. It is also seen in the literature as Alzheimer’s Dementia, Senile Dementia of the Alzheimer’s Type (SDAT), or simply AD. It is sometimes, incorrectly, called “senility.” Senility, however, is not a disease. We all experience some physical and mental changes as we age. Older people, for example, typically experience some musculoskeletal problems and some hearing and vision loss. They also may experience minor cognitive changes for which they can easily compensate. These changes are a part of normal aging.

The progressive cognitive decline triggered by Alzheimer’s disease is not part of the normal processes we associate with aging. The brain’s billions
of neurons, or nerve cells, communicate by using chemicals. In Alzheimer’s disease, nerve cells in areas of the brain responsible for memory and other thought processes degenerate for reasons which are under intense investigation by research scientists. Some of the nerve cells most damaged by the disease communicate by using a chemical called acetylcholine, which helps transmit electrical nerve impulses important to memory. The brains of people with Alzheimer’s appear to lose the ability to make acetylcholine, or to maintain acetylcholine levels in amounts necessary for normal cognitive functioning. Early in the disease process, Alzheimer’s affects nerve cells in the hippocampus, the brain’s memory center. It also disrupts the passage of electrochemical signals between nerve cells in the cerebral cortex, the brain’s outer layer. Gradually, it causes the death of cells in areas throughout the brain which control memory, perception, judgment, motor skills, and other abilities. As one person with the disease put it, “It’s as if I hear things and they get into the wrong slots, which make no sense to me at all” (Davis, 1989).

Another significantly affected area of the brain is the visual cortex which, as mentioned in the Introduction, influences our ability simply to get from one place to another, and back, without getting lost. The disease also causes disorientation and frequent difficulty relating to the environment (Roberts & Algase, 1988). This damage can and usually does lead to wandering behavior.

Alzheimer’s disease is generally defined as falling into two categories.

1. Late-onset, or sporadic, Alzheimer’s occurs in people who are typically over age 65 and represents upwards of 90% of cases.
2. Early-onset, or familial, Alzheimer’s occurs in approximately 1 to 9% of cases. Familial Alzheimer’s appears to have a definite genetic link and tends to affect people who are younger, typically in their 40s, 50s, or early 60s.

Signs of the Disease

The Alzheimer’s Association has identified ten warning signs of progressive memory loss. (See Stages of the Disease, below, for more on manifestations of the disease.)

- Recent memory loss which affects job, or other, skills. (We have all misplaced our keys or forgotten a telephone number. People with Alzheimer’s disease, however, may forget how to use the keys or the phone. And because of the short term memory loss typical of the
disease, they will become increasingly unable to absorb or retain new information.)

- Difficulty performing familiar tasks. (Cooking or serving a meal, for example.)
- Problems with language. (People with dementia forget simple words or substitute an inappropriate word for the forgotten one. A faucet may become a “water dripper,” for example. They will often repeat themselves, asking the same question many times.)
- Disorientation as to time and place. (They may forget appointments or get lost on their own street.)
- Poor, or decreased, judgment. (They may step out into heavy traffic against the lights, for example, or leave the house in a snowstorm dressed only in pajamas.)
- Problems with abstract thinking. (Alzheimer’s disease affects our ability to think logically, or to perform math. The numbers in the checkbook in time become meaningless.)
- Misplacing things. (And sometimes putting them in inappropriate places.)
- Changes in mood or behavior. (Going from calm to tears to anger for no apparent reason.)
- Changes in personality. (Including profound confusion, suspicion, or fear.)
- Loss of initiative. (Someone with dementia may require cues and prompting to become involved in a familiar activity.)

Alzheimer’s disease is by far the most common cause of these symptoms of dementing illness.

### Causes of Alzheimer’s Disease

The genetics of Alzheimer’s disease are more complex than those of most other diseases, in part because there are multiple ways in which the disease develops. There is also a need to clarify the role, if any, of nongenetic factors, although there is little compelling evidence for an infectious origin for Alzheimer’s, or for a toxic-environmental origin such as aluminum (Selkoe, 1993). Many factors contribute to the cause and progression of Alzheimer’s, and there are multiple genes involved. So far, 4 genes have been very clearly associated with the disease, although others are currently under investigation. Three of the 4—presenilin 1 (PS1) on chromosome 14,
presenilin 2 (PS2) on chromosome 1, and the amyloid precursor protein (APP) on chromosome 21—are identified with early-onset, familial Alzheimer’s disease.

For the far more common late-onset, sporadic Alzheimer’s, two genes have been identified. One of them, apolipoprotein E (APOE), was found on chromosome 19 and comes in three forms, or alleles, known as e2, e3, and e4. Every person has two alleles, one from each parent. Current thought is that the 4 to 8% of people with one or two e4 alleles are at higher risk for late-onset Alzheimer’s disease (Roses, 1995). The e4 allele on the APOE gene appears to increase the level of amyloid beta protein in the brain. Amyloid beta protein deposits, called plaques, form in the brains of people with Alzheimer’s disease. These plaques are thought to cause the brain’s nerve cells to become inflamed and die (although there is still some debate over whether the plaques are the cause or the result of cell death). Other research indicates that the APOE gene may have a stronger influence on the age of onset of Alzheimer’s disease, than on the risk of getting the disease (Breitner, et al., 1999).

Studies have also found that low education is a risk factor for Alzheimer’s. While this does not mean that people with PhDs do not get the disease, one study of nuns living in a Milwaukee convent found that low linguistic ability—determined from essays written when the nuns were in their twenties—predicted eventual development of the disease (Snowdon, et al., 1996). This study was seen as one more indication that Alzheimer’s disease may begin long before people show clinical symptoms. In fact, whatever the cause, the disease process may begin well before symptoms appear, by some estimates 20 or more years before clinical diagnosis (Snowdon, et al., 1996; Reiman, et al., 1996).

Despite the obvious complexity of Alzheimer genetics, there is compelling reason for optimism about the discovery of a cause and cure. We have learned more about Alzheimer’s disease in the last 5 years than we did in the previous 30.

Other Causes of Dementia

There are several other dementing illnesses which are both progressive and irreversible (Alzheimer’s Association, 1997). After Alzheimer’s, the most common degenerative memory disorder is vascular dementia. This type of dementia produces the same endpoint as Alzheimer’s disease but by a different process. On autopsy, it is not uncommon to find evidence of both Alzheimer’s disease and vascular dementia in the same person.
Multi-infarct dementia is one of the most common vascular dementias. It is caused by multiple small strokes, or infarcts, within the brain. Infarcts are caused when a branch of a blood vessel becomes clogged by small clots, or emboli, from the heart or neck arteries. The blockage deprives an area of brain tissue of oxygen and nutrients. The symptoms of multi-infarct dementia depend on which specific area of the brain has been deprived, and consequently damaged. Strokes in the parietal lobe, which controls spatial orientation, can cause people with multi-infarct dementia to wander and become lost. This behavior and other symptoms are similar to those in Alzheimer’s disease. Unlike Alzheimer’s, however, in which there is a slow but steady progression of symptoms, multi-infarct dementia often progresses in a step-like fashion, with symptoms “plateauing” until further infarcts cause further cognitive decline.

Pick’s disease (and related frontal-temporal lobe dementia) was once confused with Alzheimer’s, as the symptoms are similar. People with Pick’s disease, however, show a more dramatic atrophy of the frontal and temporal lobes of the brain. The disease usually begins between the age of 40 and 60. Disturbances in personality and behavior among people with Pick’s disease may precede, and be more severe than, their memory problems.

Binswanger’s disease is another type of vascular dementia, in which stroke-like changes occur in the white matter deep within the center of the brain. It is closely associated with hypertension.

Parkinson’s disease affects more than 1 million Americans (Alzheimer’s Association, 1999). It can often be treated successfully with drugs. Symptoms include a loss of control of muscle activity resulting in tremors, stiffness, and speech impediments. In the late stage, usually 10 years or more into the disease, Parkinson’s can result in a dementia similar to Alzheimer’s disease. But because the physical problems in Parkinson’s are so overwhelming, the early signs of dementia are often missed. A person with Parkinson’s dementia may lose the physical ability to button a shirt, for example, long before losing the cognitive ability necessary to perform that task. For someone with Alzheimer’s, the reverse may be true.

Lewy body disease is a relatively recently observed disorder of the brain. Its symptoms can appear as a combination of Alzheimer’s and Parkinson’s, with both cognitive impairment and abnormal physical movements.

Although the cause of brain degeneration may be different in the different types of dementia, people with these diseases seem to share cognitive and behavioral problems which put them at risk of wandering and becoming lost.

Other causes of dementia are considerably less common, and their rates of progression vary greatly. What they have in common, however, is they
are progressive, degenerative, and can produce the same confusion and disorientation which lead people with Alzheimer’s disease to wander and become lost.

*Huntington’s disease* is a hereditary disorder which causes intellectual decline and psychiatric problems, as well as involuntary movements of the limbs or facial muscles. Huntington’s can be positively diagnosed. Its progression cannot be stopped, but its physical and psychiatric symptoms can be controlled with drugs.

*Creutzfeldt-Jakob disease* is another rare and fatal brain disease which causes memory problems and affects muscular coordination. It is caused by a transmissible agent called a “prion,” and progresses very rapidly.

*Normal pressure hydrocephalus* is yet another rare disease, caused by a blockage in the flow of cerebrospinal fluid, causing a buildup of fluid on the brain. Symptoms include difficulty in walking, memory loss, and incontinence. It can sometimes be corrected with surgery, by the insertion of a shunt to divert the fluid away from the brain.

An additional and sometimes overlooked population at risk of wandering behavior includes people with mental retardation, among whom the incidence rate for Alzheimer’s disease is nearly twice that of the general population (Lai, 1992). For people with Down syndrome, which is the most common cause of mental retardation, Alzheimer’s disease is a virtual certainty. Research indicates that there may be a link between trisomy 21 (being born with an extra, or third, copy of all or part of chromosome 21), which causes Down syndrome, and a small percentage of cases of familial Alzheimer’s thought to be influenced by the APP gene on chromosome 21. On autopsy, brain tissue from people with Down syndrome shows patterns of plaques and tangles as well as chemical deficits similar to those seen in brains affected by Alzheimer’s disease. Because memory loss may be more difficult to detect in people with mental retardation—when there’s no clear baseline for short-term memory, for example—the first symptoms noticed are more likely to be personality or behavioral changes, such as wandering (Antonangeli, 1996).

There are also a number of conditions listed below which can mimic the symptoms of Alzheimer’s disease. Nutritional deficiencies and depression are noteworthy, because both can result from the neglect and social isolation too often experienced by elders, as is polypharmacy, because it describes the situation of so many elders who are prescribed a number of different medications which can cause a dangerous reaction when taken simultaneously. More germane to this book, however, is alcoholism, principally because alcoholics are disproportionately represented among homeless populations, particularly in our cities. As the homeless alcoholic ages, his continued drinking damages
brain cells and affects his orientation to time and place. As his ability to sustain himself on the street diminishes, he comes to the attention of the law enforcement, medical, and social work systems, often because he is lost and confused.

The treatable illnesses which impair memory are known as pseudodementias. They include: depression, alcoholism, drug reactions, thyroid disorders, nutritional deficiencies, brain tumors, and infections such as AIDS, meningitis, and syphilis (Alzheimer’s Association, 1997).

Prevalence Rates

There are an estimated 4 million people in the United States who suffer from Alzheimer’s disease or a related neurological disorder (Evans, et al., 1990), although an analysis of 18 different prevalence studies in the U.S. and Europe found the number to be closer to 2.1 million people (U.S. General Accounting Office, 1998). Prevalence rates are greater for women than for men, which may be due to the longer life expectancy of women. Alzheimer’s disease is the fourth leading cause of death among adults, after heart disease, cancer, and stroke (Katzman, 1976).

Over 90% of Americans with Alzheimer’s are age 65 or older (Alzheimer’s Association, 1993). One frequently cited study of prevalence rates, which assessed more than 3,600 people living in the community, found that among all those age 65 and older, 10.3% had probable Alzheimer’s. The highest rate in that study, 47.2%, occurred in those over age 85 (Evans, et al., 1989).

But while prevalence estimates in the many studies vary, there is unanimity on two points:

1. prevalence rates increase sharply with age, doubling about every 5 years up to age 85; and
2. most people with the disease are in the 75–89 age group.

These findings take on added significance in light of 1990 and 2000 U.S. Census data placing the 80+ age group among the fastest growing segments of the general population.

Diagnosis

From 12 to 19% of suspected Alzheimer’s cases prove, after a neurological evaluation using the clinical diagnostic criteria for Alzheimer’s disease, to
be some other medical condition (Tierney, et al., 1988). Since some of these other conditions—such as the alcoholism, depression, and other conditions mentioned above—are treatable and even reversible when diagnosed in a timely fashion, elder care professionals are strongly advised to pursue full diagnostic evaluations for all those experiencing memory loss, confusion, and disorientation. Accurate diagnosis is also important for other reasons. Without it, useful therapies and medications which can sometimes delay the symptoms of dementia may inadvertently be withheld. Additionally, family and professional caregivers need to know the name and nature of the disease they are dealing with before they can begin to address problem behaviors such as wandering. And just as important, people with the disease who are still able to participate in decisions about their future deserve that opportunity. In the early stage of the disease, they generally seem to be aware of their memory problems. Many people with Alzheimer’s also seem to do better after they have been told of their diagnosis. Raia (1994) speculates that this may be because they realize that they do not have an emotional illness and that their memory problems are due to a brain disease that is beyond their control. Supporting that view, a family caregiver whose husband was diagnosed with dementia wrote, “Organic (emphasis hers), physical, not psychological, not within the control of the patient. This word was a source of enormous relief to us” (Kunkemueller, 1998).

There is no single test to diagnose Alzheimer’s disease. A definitive diagnosis is only possible with a brain autopsy or, in rare cases, with a brain biopsy. The brain tissue of someone with Alzheimer’s disease is distinguished from those affected by other types of dementia by the presence of tangles of fibers, called neurofibrillary tangles, and clusters of degenerative nerve endings, called neuritic plaques, which appear in areas important for memory and intellectual functioning. As mentioned in the section Causes of Alzheimer’s Disease, these plaques are thought to cause the death of brain cells, which are not replaced. The Alzheimer’s brain literally shrinks, its weight ultimately diminished by 30 to 40%. People with the disease may lose a third of their brain mass (Roses, 1995). Another characteristic of Alzheimer’s is the reduced production of certain brain chemicals, especially acetylcholine and somatostatin, which are necessary for normal communication between nerve cells.

The highly accurate differential diagnosis is the suggested method of testing for dementia (Small, Rabins, et al., 1997), and consists of a detailed medical history, physical exam, neuroimaging techniques such as a CT scan or MRI, and neuropsychological testing. Neuropsychological testing often consists of having the memory-impaired person perform some combination
of the following: name the day, month, and year; remember three key words stated at the beginning of the exam; count backwards by seven; draw a clock with the minute and hour hands at a specified time. The more comprehensive differential diagnosis is performed by a team of clinicians, ideally with caregiver input, with the object of ruling out any other possible causes of symptoms. Some of the specialist roles outlined below are interchangeable.

**TABLE 1.1 Diagnostic Specialist Table**

<table>
<thead>
<tr>
<th>SPECIALIST</th>
<th>ROLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologist</td>
<td>Does neurological testing (EEG, CT scan, or MRI)</td>
</tr>
<tr>
<td></td>
<td>Assesses for seizures</td>
</tr>
<tr>
<td>Neuropsychologist</td>
<td>Tests memory, language, reasoning, arithmetic skills</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>Takes medical and social history</td>
</tr>
<tr>
<td></td>
<td>Assesses for clinical depression</td>
</tr>
<tr>
<td></td>
<td>Evaluates overall test results</td>
</tr>
<tr>
<td></td>
<td>Manages all medications</td>
</tr>
<tr>
<td>Internist/Geriatrician/Family Practitioner</td>
<td>Does complete physical examination</td>
</tr>
<tr>
<td>Nurse/Social Worker</td>
<td>Acts as primary care physician</td>
</tr>
<tr>
<td></td>
<td>Refers to community supports</td>
</tr>
<tr>
<td></td>
<td>Advises on behavioral management</td>
</tr>
</tbody>
</table>

**Genetic Testing**

Having a gene associated with Alzheimer's does not mean a person will develop the disease. Having the APOE-e4 gene is a risk factor, for example, but not a predictive factor. And since there is no cure for Alzheimer's, the value of genetic testing for all but a minute number of people with a clear genetic predisposition to familial Alzheimer's disease is questionable. Even then, the rare person knowing he or she has a causative gene may experience unnecessary anxiety, anger, depression, and stress. And although various legislation has been introduced to address genetic discrimination, such discrimination by insurers, or employers, remains a possibility. The Alzheimer's Association strongly recommends that anyone planning a genetic test also undergo pre and posttest counseling. This advice should be taken into consideration by anyone considering genetic testing for any dementing illness.

**Life Expectancy**

Average life expectancy from the appearance of symptoms—not from point of diagnosis or point of contact with the elder service system—is just over
8 years (U.S. Congress, 1987), with symptoms usually occurring 2–4 years before diagnosis (Berg & Morris, 1994). As mentioned under Causes of Alzheimer’s Disease, however, the slow disease process may begin decades before clinical symptoms actually appear. Although 8 years is the average life expectancy from the appearance of these symptoms, people with Alzheimer’s can sometimes live for 20 years or more from that point. Caring for them all too frequently depletes families of their physical, emotional, social, and financial resources.

Stages of the Disease

Alzheimer’s disease progresses in three loosely defined stages. People with the disease gradually lose their orientation as to time, place, and person, roughly in that order. Damage to particular skills related to time, place, and person may overlap, however, because many functions, including memory, occur in widely dispersed areas of the brain. Our emphasis in this book is on the early and mid stages of the disease, delineated below, when people with dementia are more mobile and thus more apt to wander and become lost.

Early stage

Early on, people are often aware of their illness and require less supervision. With support, they carry on with minimal changes in lifestyle. This is not to say that they do not wander and become lost in this early stage of the disease. They do. The difference at this early point is that they still have the cognitive ability to ask for help, to recall where they live, or even, depending on the stress of the moment, to recall a phone number. The usual early-stage duration is 1 to 3 years. Areas of decline include:

- Short-term memory
- New learning
- Language (especially word-finding problems)
- Planning and calculation
- Behavior (e.g., impulse or temper control, lowered inhibitions)
- Personality (e.g., flattened affect, frustration, less drive)
- Cognitive mapping (i.e., getting from point A to point B and back without getting lost)
- Fine motor control and reaction time
- Work productivity
Doing complex tasks and understanding directions
Depression

Middle stage

In the broad middle stage of the disease, people are unable to perform everyday tasks without supervision. They have poor memory of the recent past but may still remember more distant events. There is increased disorientation to time, in particular, and also to place and person. The usual duration is 2–8 years. Additional areas of decline include:

- Judgment
- Decision-making
- Expressing and understanding language, word repetition
- Expressing emotions appropriately
- Recognizing familiar people
- Personal safety (e.g., getting lost)
- Independence related to activities of daily living (the ADLs—e.g., bathing, dressing, toileting, grooming, eating)
- Psychiatric health (e.g., anxiety, paranoia, hallucinations, and the catastrophic reactions, or super anxiety attacks mentioned below under Psychiatric issues)

Late stage

In the late stage of the disease, people are usually unable to communicate, have poor recent and remote memory, are apathetic, and require complete care. The usual duration is 1–3 years. Final areas of decline include:

- Mechanics of chewing and swallowing
- Major organs controlled by the autonomic nervous system

While still physically active and able to communicate, as in the early or mid stages of the disease, people with Alzheimer’s can nevertheless have difficulty with the critical analysis involved in making simple judgments and decisions (Moss & Albert, 1988). People moderately impaired with Alzheimer’s can also have great difficulty with routine activities of daily living, such as preparing and eating their food, paying bills, and maintaining personal hygiene. As mentioned, these difficulties extend to such simple tasks as finding the way from one familiar point to another. As the person’s
cognitive mapping skills progressively and inevitably diminish, wandering, in particular, becomes a life-threatening behavior.

The following case not only provides an example of that particular difficulty, but also illustrates just how deceiving appearances can be when we attempt to gauge risk in Alzheimer’s disease.

Mr. E. took the same one-mile walk each day, which involved negotiating a busy intersection near his home in the city. He was reported to state Elder Protective Services by police after becoming lost on three occasions, and the Protective Services caseworker asked that Alzheimer’s Association representatives sit in on a family conference. Otherwise quite caring, the family refused to recognize the risks associated with these walks. Nor was the Protective Services worker altogether convinced of the degree of risk when Mr. E.’s son, after accompanying his father on one such walk, reported that his father went directly to the crosswalk at the intersection and waited for the WALK signal before stepping off the curb.

That behavior not only seemed to demonstrate his father’s awareness of the fast moving cars and trucks in the street, but convinced the son that his father still had the intellectual capacity to avoid the potential danger they posed. Since habit and analysis (of visual information, in this instance) are two different things, our interpretation of Mr. E.’s actions was very different. By going to the crosswalk, Mr. E. was reacting to his less compromised long-term memory. And by waiting for the pedestrian light before stepping into the street, he was reacting to cues from his son, who had remained at his father’s side on the curb until the appropriate signal flashed.

We suggested the son once more accompany his father on the same walk, but this time stay a short distance behind his father and not alert him to his presence. Once again, the son reported that his father went directly to the crosswalk, looked up at the traffic signal—which read DO NOT WALK—and did indeed look both ways at the heavy traffic before stepping right into it. The son was close enough to draw him back safely. He returned home as convinced as we were that pure luck alone had been keeping his father alive (Flaherty & Raia, 1996).

**Excess Disability**

Excess disability is a common term associated with Alzheimer’s disease and describes the loss of capacity by someone with the disease to perform a specific task—dressing herself, for example—before that capacity is likely to be lost, given the stage of the disease. It has been defined as having more cognitive impairment than can be explained by the disease itself. According to the Alzheimer’s Association (1993), “Causes of excess disability can include intercurrent illnesses, pain, medications, or poor hearing/vision.” While some of the following conditions may correspond to what could reason-
ably be expected at a given stage of Alzheimer’s disease, others may not. For someone with the disease who wanders and becomes lost, these various disabilities, whether “excess” or not, have both medical and psychiatric implications which considerably elevate the risk of harm.

Medical issues

There are more burn injuries to the elderly than to all others in the United States except those under age two, and the risk of such injuries is compounded by dementia (Petro, et al., 1989). Mental status, as well, significantly increases the risk of injury from falls among the elderly (Morse, et al., 1987). As for general physical health, people with dementia have been shown on average to have more than three coexisting medical conditions (U.S. Congress, 1990), including, among other problems: hearing impairment, cardiac illness, arthritis, and hypertension (Figure 1.1). Older people in general are more susceptible than others to hypothermia and dehydration. The added medical problems of older people with Alzheimer’s disease who wander from home or a facility and become lost only magnify their physical vulnerability.

Psychiatric issues

A study of 217 mild to moderately impaired people with Alzheimer’s disease, all of whom were living in the community, found that they experienced

![Coexisting medical conditions](image)

**FIGURE 1.1** Coexisting medical conditions.
the following psychiatric complications: depression, paranoia, anxiety and fearfulness, delusions, aggressive acts, and hallucinations (Figure 1.2) (Mendez, et al., 1990).

Another study followed 32 recently diagnosed people with Alzheimer’s for 6 years, all of them living in the community, and found that symptoms of psychosis only worsened as the disease progressed (Rosen & Zubenko, 1991).

Before continuing, however, we would add a clarifying note on aggressive behavior. A study by Gilley and colleagues (1997) found that nearly 80% of aggressive behaviors occurred during a care-related activity like dressing, bathing, or toileting, all of which involve close, even intrusive, physical contact. Further, the aggressive actions were more common among people in the later stages of Alzheimer’s disease, who are more confused. Since these people require more care, there is a greater opportunity for aggressive or, to use a more appropriate term in light of Gilley’s findings, “reactive” behavior.

In any event, the effect of these various psychiatric issues on someone with Alzheimer’s disease who wanders and becomes lost compounds the risks posed by the more obvious medical issues. Any one of these issues can completely obviate whatever ability that person might have had to find his or her own way home, or even to ask for help. Additionally, a behavioral
phenomenon called *catastrophic reaction* is not uncommon among people with Alzheimer's under stressful conditions. This is a sort of super anxiety attack, usually lasting 15–20 minutes. It usually involves crying and pacing, but can include agitated behavior such as throwing things or knocking things over. Of special note here, a catastrophic reaction can also include running away from a caregiver. Worse yet, in a number of cases (see Chapter 10) where a wanderer has been missing for several hours or more, it includes getting into dense brush and other generally inaccessible and overlooked places, with disastrous results.

Family caregiving issues

The well caregiver is not immune to a type of excess disability, in that the typical family caregiver is a woman in her 70s who has three chronic medical problems of her own to deal with in addition to her spouse’s dementia (Alzheimer’s Association, 1990).

A caregiver whose husband’s body was found less than a quarter of a mile from their home following a wandering incident typifies many of these problems. “I’m 79 years old and I have a heart condition,” she told an Alzheimer’s Association representative. “I just couldn’t chase after him.”

Caregiving takes an obvious toll. In addition to the attendant medical problems, providing care for someone with dementia has long been recognized as a cause of stress, a circumstance aptly caught in the title of one of the best-selling books for caregivers, *The 36-Hour Day*. The lengthy experience often leads to depression in family caregivers. Some studies have reported that nearly 50% meet the diagnostic criteria for depression (Raia, 1994). Sleep disturbance was cited by 70% of family caregivers as a reason for nursing home placement (Pollak & Perlick, 1987). The effects of their experience on caregivers’ preexisting medical conditions is palpable. In one study (Chenoweth & Spencer, 1986), about 21% of family caregivers institutionalized relatives because the caregivers themselves became ill or injured. Most of those caregivers were spouses in their 60s or 70s.

Specific interventions will be discussed in future chapters, but it should be said here that family support groups provide a helpful forum for caregivers to share feelings, concerns, and information, and to assist one another in coping with the psychological effects of caring for someone with dementia.

Driving issues

We mention driving in this section only because the automobile represents an instrument of potentially instant disability, excess or otherwise. We will
discuss Alzheimer’s wanderers who become lost while they are driving in a later chapter. But for the moment, a brief review of some of the literature on driving and Alzheimer’s may be helpful. While the research regarding the driving skills of people mildly impaired with Alzheimer’s disease may not offer hard and fast recommendations, no researcher debates the need for regular retesting and constant vigilance of even the most mildly impaired patients who drive (Kapust & Weintraub, 1992; Hunt, et al., 1988). A study conducted at Johns Hopkins University found that over 40% of people with early Alzheimer’s who drove had been in an accident after their diagnosis and that 44% routinely got lost (Lucas-Blaustein, et al., 1988). Furthermore, researchers who examined the brains on autopsy of elderly people who died in car crashes found that one-third showed clear evidence of early stage Alzheimer’s disease (Johanson, et al., 1997).

But, as the following case indicates, relinquishing the car keys may be problematic:

Mr. J., with a 2-year-old diagnosis of Alzheimer’s disease, dependent on cognitive cueing by his wife to dress himself but insistent on driving his car, claimed that he would most certainly know when he should stop driving. “When I’ve had an accident,” he said. Incredibly, both his family and his caseworker were comfortable with this line of reasoning (Flaherty & Raia, 1994).

What was needed in this case (literally an accident waiting to happen) was a real-life demonstration, through the state’s Department of Motor Vehicles or other appropriate testing center, of Mr. J.’s capacity to drive safely.

Here are some things to consider in assessing when someone with Alzheimer’s needs to stop driving: Alzheimer’s disease affects reaction time and visual-spatial relationships; wanderer cases take much longer to resolve when the lost person is driving; and the risk is not only to the person with Alzheimer’s but to the public. Additionally, the American Psychiatric Association has recommended that doctors write prescriptions directing people with Alzheimer’s not to drive, based on evidence that they are more likely to cause crashes, even in the earliest stages of the disease (Associated Press, 1997).

People demonstrate many different capacities in their daily lives—they bathe and dress themselves, plan and cook meals, make financial decisions, give advice to their children. For someone with Alzheimer’s disease, however, the competence to perform in these “capacities” can exist at different levels at different times. Typically, people with Alzheimer’s lose their awareness of their deficits, and if they are aware, will minimize them. There is another distinction to keep in mind when assessing the risks faced by people with Alzheimer’s disease: “No” may mean something else, such as “I don’t under-
stand," or "I'm afraid." It is important to learn to respond not only to the words, but to the emotions behind them.

Treatments

There is accelerating activity in several treatment areas, often in cooperation with the Alzheimer research centers funded by the National Institutes for Health, and with funding of research by the Alzheimer's Association.

Currently 4 drugs are approved by the U.S. Food and Drug Administration specifically for Alzheimer’s. They are available only by prescription. Their costs are covered by some health insurers. They act by inhibiting the enzyme acetylcholinesterase, thereby slowing the breakdown of acetylcholine in the brain. Increasing the amount of acetylcholine in the brain allows nerve cells to communicate better and thus improves memory. Unfortunately, none of these drugs prevents cell death, and once the disease progresses to a stage when there is little acetylcholine left in the brain, they lose their effectiveness.

Treatment of dementia caused by vascular disease and stroke, such as multi-infarct dementia and Binswanger’s disease, also involves the treatment of underlying conditions such as heart disease, high blood pressure, diabetes, smoking, or high cholesterol levels. Treating these risk factors can sometimes slow the progression of these types of dementia.

While there are many other pharmacological and, potentially, genetic treatments in development, it is a better understanding of the psychology of dementia—how a person thinks, feels, communicates, compensates, and responds to change, to emotion, to love—which may bring some of the biggest breakthroughs in treatment. An entire therapeutic model, called Habilitation Therapy, has been built on the premise that the last brain function to fail in people with dementia is the ability to feel and express emotion (Raia & Koenig-Coste, 1996).

In fact, according to a report on current treatments by Lombardo (1997) in the newsletter of the Alzheimer’s Association’s Massachusetts Chapter, it was a psychoeducational intervention targeting family caregivers in the home which has had the biggest impact to date on how long people with dementia stay alive, functional, and living at home. In a study of 206 people with dementia and their caregivers, the caregivers received initial, intensive individual and family counseling, with continuously available follow-up counseling and support groups. After 8 months, these caregivers were less likely to be depressed than caregivers in the control group, a benefit which not only persisted after completion of the counseling interventions, but also was magni-
fied if the interventions continued over time. Patients in families receiving
the interventions remained at home 11 months longer than patients in the
control group, and their caregivers were only two-thirds as likely as caregivers
in the control group to place them in nursing homes (Mittelman, et al., 1996).

A number of alternative treatments aimed at delaying onset of the symp-
toms of Alzheimer’s disease are also under investigation. There are multi-
site, federally funded studies of ginko biloba, an herbal substance, which
may help to increase blood flow in the brain, and of certain nonsteroidal
anti-inflammatory drugs which may help to reduce the swelling of brain tissue
associated with nerve damage in Alzheimer’s disease. Also, epidemiological
studies of women taking estrogen replacement therapy seemed to show a
delay in the onset of Alzheimer’s disease (Brenner, et al., 1994). And antioxi-
dants such as vitamin E continue to be examined. Information about other
potential “natural” treatments for the symptoms of Alzheimer’s disease can
be found on the Web site of the National Institutes of Health. Some of these
substances can have serious side effects. Before taking any substance for any
symptom of memory loss, consult a physician. Specific therapeutic interven-
tions for specific professions will be discussed in later chapters. We would
only say here, by way of summary, that some of the best interventions
currently available are those which: educate the family caregiver about behav-
ioral management techniques; offer emotional support; engage the person
with Alzheimer’s in failure-free, therapeutic activities on a daily basis; allow
for respite during the week at an Alzheimer adult day health center; modify
the home environment to ensure safety and a sense of security; evaluate the
person’s need for medical treatment, including medications; and monitor the
physical and emotional health of both the person with Alzheimer’s and
the caregiver.

Additionally, some Alzheimer facilities are specifically designed to keep
residents as safe and independently functioning as possible. Placement in a
therapeutically sound, properly supervised setting such as an Alzheimer’s
special care unit in a nursing home or an assisted living facility with an
Alzheimer’s component can be the best intervention for the people with
Alzheimer’s who are most at risk.

Finally, while there is good reason for optimism about research break-
throughs as to the causes of and cures for Alzheimer’s disease, a supervised,
structured daily schedule is still the most potent medicine for this disease
and for the problem behaviors, such as wandering, which are associated with
it. Our shared goal must be to find the best supportive and safe environment
for people with dementia.
Credit: The diagnostic specialist table (Table 1.1) and bulleted information on areas of decline are from Of Two Minds: A Guide to the Care of People With the Dual Diagnosis of Alzheimer’s Disease and Mental Retardation (1996). Reprinted with permission of J. Antonangeli.