Clinical Alzheimer Rehabilitation

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The aging of baby boomers is a frequent news topic because of the impact on the social-support systems this large group of people reaching age 65 will have. What is clear is that with the increasing numbers of individuals living longer the greater the number of people are suffering from Alzheimer’s disease. As discussed in this book, the incidence of Alzheimer’s disease is 18% in those age 75–85 and then increases to about 47% in people age 85 and older. Our improved health care has resulted in a large population of people age 75 and older. These figures speak to the cost, both emotional and financial, to all of us as the number of individuals with Alzheimer’s disease increases. Society must find effective ways to slow the progression of Alzheimer’s and develop effective and efficient strategies to meet the needs of those with this challenging disease. Support of research aimed at preventing the disease should have the highest priority in government funding but that has not materialized. The lack of a cure and an effective form of treatment means that every possible means of slowing the disease and its manifestations must be utilized.

As a physical therapist for 50 years involved in the care of individuals with dementia as well as my firsthand experience with family and friends with Alzheimer’s disease, I am acutely aware of the challenging aspects of this disease. Drs. Gogia and Rastogi have provided here a valuable resource to all those involved with individuals with Alzheimer’s disease. This book provides a very thorough coverage of all aspects of the disease and is written in a way that meets the needs of the general public as well as health care professionals.

One of the appealing aspects of the book is that one of the authors is a physical therapist. At the time of this writing, one of the most effective forms of treatment for slowing the progression of Alzheimer’s disease is 30 minutes of aerobic exercise 3 times per week. Yet in the age group experiencing the disease, being able to exercise has many considerations. Older individuals often have musculoskeletal problems such
as degenerative disease of the spine, hips, knees, and feet in addition to the sarcopenia that is present with aging and inactivity. Thus, designing an effective exercise program becomes a particular challenge. The chapter on rehabilitation emphasizes and has useful suggestions about maintaining patients with Alzheimer’s disease, which includes exercising regularly and participating in as much activity as possible. The use of medication is certainly an easier treatment route but as with many health care problems, the benefits of exercise are many and the side effects are few, particularly if the program is designed by a therapist.

Although this book incorporates a wide variety of strategies and resources for treatment, the realistic approach to long-term care and the end-of-life issues is particularly well done. Reading this book will enable health care providers and family caregivers to be well prepared for what to expect for the entire course of the disease. If knowledge and preparation are the best defense and offense for being able to manage challenges, then this book is an excellent way to obtain those tools. I highly recommend this very readable and invaluable book.

Shirley Sahrmann, PT, PhD, FAPTA
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Alzheimer’s disease, the most common form of dementia, is a progressive and degenerative brain disorder that results in symptoms such as loss of memory, impaired judgment and reasoning, difficulty with day-to-day functioning, and changes in mood and behavior. As the population ages, the number of people diagnosed with Alzheimer’s disease will increase dramatically, as will the cost of care for people with Alzheimer’s. Rehabilitation is a vital part of management of this challenging disease. Current research on physical rehabilitation in people with Alzheimer’s disease is very limited. In addition, researchers are reluctant to conduct clinical trials with Alzheimer’s simply because of communication difficulties, logistical problems, ethical difficulties, and methodological challenges. Furthermore, investigators also believe that the indicators of success are difficult to measure. It is important to remember that, although any skills lost will not be regained, rehabilitation gives special consideration to quality of life for people with Alzheimer’s disease. This comprehensive book is written to act as an up-to-date resource for those clinicians and caregivers who are involved in the care of people affected by Alzheimer’s disease, either directly or indirectly. Particular attention has been paid to the rehabilitation aspect of management for this challenging population. All that we know about Alzheimer’s disease is not being practiced. There are “tools of the trained”—caregiving and diagnostic tools—that have been proven to help arrest Alzheimer’s disease. Illustrations and tables are included as needed to enhance the clarity of the text. We hope this book, which is based on these tools and on the newest developments in Alzheimer’s research, can serve as the first complete resource for clinicians and caregivers.
We wish to thank the following colleagues for their support in reviewing the manuscript and for providing valuable suggestions:

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Over the next century, experts estimate that Alzheimer’s disease will be more prevalent than AIDS, cancer, and all cardiovascular diseases.

World Health Organization

In 1994, former President Ronald Reagan made a public announcement that touched the hearts of millions of Americans. The President and Mrs. Reagan, each of whom had already survived cancer, were up against their next challenge: “I have recently been told that I am one of the millions of Americans who will be afflicted with Alzheimer’s disease,” President Reagan said in a handwritten letter to the American people (Reagan, 1994). “Upon learning this news, Nancy and I had to decide whether, as private citizens, we would keep this a private matter or whether we would make this news known in a public way.”

The President’s announcement was a bold one. At the time, just over a decade ago, Alzheimer’s disease (AD) was clouded in mystery—an alarming diagnosis that was best kept behind closed doors. Medical research on Alzheimer’s had gained momentum, but the number of undiagnosed cases remained high. Reagan, who was an active partner of the Alzheimer’s Association until he passed away in 2004, understood the value of shedding light on the disease: “In opening our hearts, we hope this might promote greater awareness of this condition. Perhaps it
will encourage a clear understanding of the individuals and families who
are affected by it.”

President Reagan wasn’t alone in his plight. In 1995, a year after
he disclosed his diagnosis, an estimated 377,000 new cases of AD were
reported in the United States (Hebert, Beckett, Scherr, & Evans, 2001).
Alzheimer’s disease afflicts 1 in 10 people over the age of 65 and nearly
half of all people age 85 and over (Mintzer & Targum, 2003). People with
Alzheimer’s live an average of 8 years, although some live up to 20 years or
more after the first onset of symptoms (Hingley, 1998). With an average
lifetime cost-of-care per patient of $174,000, it is the third most expen-
sive disease in America, following only heart disease and cancer (Ernst &
Hay, 1994). Today, approximately 4.5 million Americans have the disease
and are learning to live with its inevitable effects (Hebert, Scherr, Bien-
ias, Bennett, & Evans, 2003)

UNDERSTANDING ALZHEIMER’S DISEASE

Alzheimer’s disease, the most common cause of dementia, is a progres-
sive, irreversible neurologic disorder that develops over a period of
years. It is age related and is characterized by changes in behavior, per-
sonality, judgment, and the ability to perform usual activities. The classic
triad for patients with AD is memory impairment, visuospatial defects,
and language changes. These changes occur in the absence of confusion,
mental retardation, or other neurologic disorders and represent a con-
siderable decline from a patient’s usual level of functioning.

The course of AD varies from person to person, as does the rate of
decline. In most people with AD, symptoms first appear after age 65.
The risk of developing AD increases with age, but AD and dementia
symptoms are not a part of normal aging.

Normal Aging Versus Alzheimer’s Disease

Alzheimer’s disease is a complex illness that is still not completely under-
stood by the medical world. As a result, many myths and misconceptions
prevail about AD. It is not only laypeople but some physicians, too, who
lack a proper understanding of this disease.

One thing is certain: AD causes dementia. Alzheimer’s disease ef-
fects are gradual, resulting from the slow death of nerve cells in the brain
that are vital for memory and other functions, such as speaking, comprehending, reading, abstract thinking, and calculating (Kuhn, 1999). Martin Rossor (2003) offered a simple way to understand the relationship between AD and dementia. Dementia is a syndrome that is associated with many different underlying diseases. “In a sense, it is similar to heartburn or headache, which is caused by many different things, and could require many different treatments,” said Rossor. Alzheimer’s disease is the most common cause of dementia.

Both AD and dementia are discussed in more detail in chapter 2. For now, it is important to understand that neither AD nor dementia is a natural process of aging.

To distinguish a person undergoing the natural aging process from one with AD, let’s compare symptoms of each.

**Scenario 1: Forgetfulness**

Most elderly persons have occasional lapses in memory. But how can one differentiate symptoms of dementia from normal signs of aging? Consider this example: it is normal for people, as they get older, to forget things like where they put their glasses or where they last placed their keys, but, given a medical test on memory and thinking, they would most likely perform very well (Kuhn, 1999).

Changes in memory and mental ability with normal aging are quite mild and do not continue to get worse over time, nor should they interfere with a person’s day-to-day functioning. Normal age-related changes consist primarily of slight changes in memory and learning and processing information a bit more slowly.

The key difference between dementia and what’s happening with the “forgetful old man” is that dementia involves loss of memory functions and at least one other domain of cognitive impairment (i.e., language, thinking, or perception) (Rossor, 2003).

In contrast, patients with dementia suffer from worsening memory loss and demonstrate difficulty in other daily functions, which can appear as forgetfulness to an outside observer. People with AD may present the following symptoms:

- Confusion
- Difficulties with language (e.g., not being able to find the right words for things)
- Difficulty with concentration and reasoning
- Problems with complex tasks like paying bills or balancing a checkbook
- Problems with orientation or spatial ability (e.g., getting lost in a familiar place)

Often, it is the patient’s family that speaks to the physician about a continuing decline of mental abilities, particularly problems remembering recent information, since patients with actual dementia may be unaware or at least do not complain of problems.

**Scenario 2: Senility**

Another incorrect belief equates AD with “madness” or senility. As AD progresses, the decline in cognition continues, and personality and behavioral symptoms are more likely to appear. These are a few symptoms of AD that an outside observer may mistake for senility:

- Increased anger, hostility, and/or suspicion
- Aggression and physical violence
- Hallucinations
- Delusions
- Wandering
- Increased number of physical accidents

Although some AD patients have abnormal behavioral symptoms, caregivers must understand that these are an integral part of the disease process. The patients are unable to control their behavior, and therefore, appropriate treatment is necessary.

Often, caregivers of the elderly assume that since old age cannot be reversed, it is futile to seek medical help when a loved one is demonstrating signs of “senility.” Under no circumstances should such behavior be considered “madness.” The fact is, AD is *not* “normal old age.”

Every elderly individual does not have nor will not have this disease. It is important to be aware of the signs and symptoms that may suggest this disease and to consult a qualified medical practitioner to assess the person professionally. Table 1.1 present differences between normal signs of aging and dementia.

We have also included several excellent sources for learning more about other brain disorders at the end of this book (see Additional Resources).
DIFFERENCES BETWEEN NORMAL SIGNS OF AGING AND DEMENTIA

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<th>NORMAL</th>
<th>DEMENTIA</th>
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<tr>
<td><strong>Early signs of Alzheimer’s disease</strong></td>
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<td><strong>Memory and concentration</strong></td>
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<tr>
<td>■ Periodic minor memory lapses or forgetfulness of part of an experience.</td>
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<td>■ Occasional lapses in attention or lapses in attention or concentration.</td>
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<td><strong>Mood and behavior</strong></td>
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<td>■ Temporary sadness or anxiety based on appropriate and specific cause.</td>
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<td>■ Changing interests.</td>
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<td>■ Increasingly cautious behavior.</td>
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<td><strong>Later signs of Alzheimer’s disease</strong></td>
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<td><strong>Language and speech</strong></td>
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<tr>
<td>■ Unimpaired language skills.</td>
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<td><strong>Movement coordination</strong></td>
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<td>■ Increasing caution in movement.</td>
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<td>■ Slower reaction times.</td>
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<td><strong>Other symptoms</strong></td>
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<td>■ Normal sense of smell. No abnormal weight changes in either men or women.</td>
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<td>■ Misplacement of important items.</td>
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<td>■ Confusion about how to perform simple tasks.</td>
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<td>■ Trouble with simple arithmetic problems.</td>
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<td>■ Difficulty making routine decisions.</td>
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<td>■ Confusion about month or season.</td>
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<td>■ Unpredictable mood changes.</td>
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<td>■ Increasing loss of outside interests.</td>
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<td>■ Depression, anger, or confusion in response to change.</td>
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<td>■ Denial of symptoms.</td>
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<tr>
<td>■ Difficulty completing sentences or finding the right words.</td>
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<td>■ Inability to understand the meaning of words.</td>
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<td>■ Reduced and/or irrelevant conversation.</td>
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<td>■ Visibly impaired movement or coordination, including slowing of movements, halting gait, and reduced sense of balance.</td>
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<td>■ Impaired sense of smell. Severe weight loss, particularly in female patients.</td>
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Alzheimer’s Disease: A Silent Disease

Since AD and dementia are so intertwined, the perception of a person with Alzheimer’s tends to be distorted. It is a common belief that everyone with AD suffers from severe loss of orientation and is unable to function on his own—but these characteristics are associated with the disease’s later stages. The truth is that most people with AD have a mild form of the disease and usually die from another ailment before it progresses to more advanced stages. The subtlety of the disease is yet another reason it is often overlooked and misdiagnosed as old age.

There is no doubt that, at its worst, AD can forever alter the lives of those affected. People with Alzheimer’s who do survive to the disease’s later stages require constant supervision, which often places tremendous emotional and financial stress on the loved ones who must care for them. Watching a parent or spouse lose his or her independence is already a painful experience, but adjusting to a new role as caregiver can be equally taxing.

It is important to know the simple truths behind AD. Currently there is no cure, but a diagnosis is certainly not the end. Dr. David A. Bennett (1999), Director of Rush Alzheimer’s Disease Center, puts it best: “You do not wake up in the morning with Alzheimer’s disease, as would be the case with a stroke or heart attack. Alzheimer’s is an insidious disease.” Since the disease emerges gradually, people can take steps to prepare themselves and their families for the challenges that lie ahead.

The Race Against Time

Perhaps it is fear that keeps many heads turned away when the topic of AD arises. But no one should remain blind to the staggering facts: AD is a universal threat. It is predicted that by 2020, 30 million people in the world will be affected by the disease and that by the year 2050 the number could increase to 45 million around the world (Rishton, 2005). Right now in the United States alone, one in every three families is affected by AD (American Health Assistance Foundation, 2006). Without a cure, the chance that a person will have to deal with the condition is only increasing as time goes on. Figure 1.1 demonstrates the dramatic increase in the number of new AD cases that is expected up to the year 2050.

Where is this sharp increase coming from? Many believe it is a combination of two key trends. First is the aging of the baby boom
generation—the 77 million Americans born between 1946 and 1964 who make up approximately 28.6% of the U.S. population (Metlife Mature Market Institute, 2005). The baby boomers have reached or are close to reaching their 60s, and this “age wave” has been a hot topic of discussion among policymakers in the employment and health care sectors. Second is the advancement of medicine. The likelihood that an American who reaches the age of 65 will survive to the age of 90 has nearly doubled over the past 40 years—from just 14% of 65-year-olds in 1960 to 25% as of this writing, in 2008. By 2050, 40% of 65-year-olds are likely to reach age 90 (Civic Ventures, 2006). While these trends should give us reason to celebrate, they also give rise to some major concerns, especially in the context of AD. The 

*Journal of the American Medical Association* (Table 1.2) presents estimated prevalence of Americans diagnosed with AD.

What this means is that the “age wave” is a double-edged sword. As more Americans survive well after their 60s, their chances of developing AD continually increase. It is predicted that 14 million Americans may have AD by the year 2050, and if this trend continues, one out of every two baby boomers may develop Alzheimer’s as they reach their senior years (American Health Assistance Foundation, 2006). Figure 1.2 and Figure 1.3 demonstrate the significance of this trend.

**Figure 1.1** Projected increase in new Alzheimer’s disease cases through 2050 (number in thousands).

All of these statistics point to one thing: we are looking at a time crunch when it comes to finding a cure for AD. People in their 50s are the fastest growing population segment; every 7 seconds, someone in America turns 50 (Solovitch, 2008). This race against time is real. In the words of Daniel Kuhn (1999), “Alzheimer’s disease may well become the most pressing health problem of the baby boomers and their offspring.”
The financial cost of AD is already a cause for concern. Not only do people with AD have to pay out of pocket for long-term care and prescription drugs, but Medicare covers the cost of basic health care for them and their caregivers, who often suffer from more health problems than their peers (Charity Wire, 2004). Presently, the national direct and indirect costs of caring for individuals with AD are at least $100 billion (Ernest & Hays, 1994). American businesses are losing $61 billion every year, $24.6 of which covers AD health care and $36.5 billion of which covers costs related to caregivers due to lost productivity, absenteeism, and worker replacement (Koppel, 2002).

Stephen McConnell, Vice President of the Alzheimer’s Association, has said, “This imminent epidemic of Alzheimer’s disease threatens to bankrupt Medicare and Medicaid.” McConnell’s concern was based on a study prepared by the Lewin Group, which predicted that the Medicare costs of AD treatment will soar from $31.9 billion in year 2000 to $49.3 billion in 2010 (Tarapchak, 1998). As scary as these numbers are, they can also help us measure the impact of increased funding for Alzheimer’s research.

**Figure 1.3** Risk of Alzheimer’s disease with increasing age.
Research and Funding Can Make Difference

Without medical and social advancements, AD will become an enormous public health problem. Medical interventions that could delay disease onset even modestly would have a major public health impact.

According to McConnell (Tarapchak, 1998), if every person with AD could delay nursing home placement by just 1 month, it would save the nation $1 billion a year. “By delaying the onset of AD for even 5 years, we can keep half of the baby boomers who are now at risk from even suffering the devastating effects of the disease,” said McConnell.

Researchers (Brookmeyer, Gray, & Kawas, 1998) have reported that if interventions could delay onset of the disease by 2 years, after 50 years there would be nearly 2 million fewer cases than projected; if onset could be delayed by 1 year, there would be nearly 800,000 fewer prevalent cases (Figure 1.4). If onset could be delayed by 5 years, it would decrease prevalence in 2050 by nearly 44%. Even a 6-month delay would reduce prevalence in 2050 by 6%.

As these projections indicate, the impact of AD research is tremendous because every bit of new knowledge is a milestone. Since 1982, the Alzheimer’s Association has been the largest private funder, awarding $150 million in research grants in the hope of learning more about the disease. As more people have come forward to advocate support of

![Figure 1.4](image_url)  
**Figure 1.4** Potential impact of interventions to delay Alzheimer’s disease onset.  
Alzheimer’s research, more dollars have been allocated to discover its causes, best treatment, and an eventual cure. In 2003, the federal government reported spending $640 million on AD research—quite a jump from the 12 grants that were awarded in 1975, which totaled $700,000 (Coste, 2004). Progress is clearly being made on all fronts when it comes to slowing down the effects of AD.

Knowledge Is Power

Scientists have made significant progress in terms of prevention, diagnosis, and treatment of AD. Many new medications have been released to mitigate some symptoms of AD, and many others are still pending approval. Here are just a few examples of the new research areas on AD (note that findings are under development and have not been conclusive as of yet):

- The National Institute on Aging (2002) announced that people with AD often have low amounts of folic acid, so adjusting the diet to include more folic acid might be a first step in prevention.
- Researchers at Case Western Reserve University (2000) found that people who were less active were three times more likely to have AD than people who were more active.
- Studies done at the Salk Institute (2002) showed that neurogenesis—the creation of neurons—is possible in humans. If scientists could restore neurons lost to AD, reversing the disease could be possible.

With continued research, it is possible that one day Alzheimer’s will no longer be a threat to our future. A cure for AD, or a treatment that will slow down its progression, might be just around the corner.

Education is essential. The more we all understand AD, the better able we’ll be to provide proper care and treatment and ultimately improve life for everyone affected by AD.

WHAT THIS BOOK CAN OFFER

Even though there are resources available for those living with AD, the extensive research being conducted in the field makes it difficult for clinicians and caregivers to stay abreast of new developments, which is where this book comes in.
This book is written to act as an up-to-date resource for those clinicians and caregivers who are involved in the care of people affected by AD and dementia, either directly or indirectly. Particular attention has been paid to the rehabilitation aspect of management for this challenging population.

There are many books and articles that have been written to raise public awareness and share personal experiences of people living with AD. This book is a compilation of facts from these excellent guides, which we hope will reinforce awareness and shed light on new advancements that might not be familiar to many people. This book will also help caregivers and family members who take care of patients with AD and dementia at home or in long-term-care facilities.

All that we know about AD is not being practiced. There are “tools of the trained”—caregiving and diagnostic tools—that have been proven to help arrest AD. We hope this book, which is based on these tools and on the newest developments in Alzheimer’s research, can serve as the first complete resource for clinicians and caregivers.

The Underlying Philosophy: Diagnosis and Treatment Tools

Care of people with AD is a challenging task but—according to medical organizations that met in 2002 to discuss strengths and potential pitfalls in the diagnosis and treatment of AD—treatment can be improved. The foundation of this book is composed of key principles that have been agreed upon by clinicians, researchers, and medical organizations that provide services to Alzheimer’s patients and their families.

Seven organizations—the American Academy of Neurology, the Alzheimer’s Association, the American Medical Association, the American Association of Geriatric Psychiatry, the American Geriatric Society, the American Medical Directors Association, and the World Federation of Neurology—determined that more than two dozen practice guidelines exist to provide guidance to clinicians, yet many caregivers may not be taking advantage of the guidelines available. The following important principles in caring for people with AD were emphasized:

1 Our Alzheimer’s I.Q.

Alzheimer’s disease is recognizable and can be differentiated from normal aging by clinicians.
2 **First Family First**  
Symptoms are usually first identified by family members and should be reported to the family physician.

3 **Alzheimer’s Accuracy**  
Alzheimer’s can be diagnosed with 95% accuracy, the same as appendicitis.

4 **Elder Care Full**  
Effective care options exist and can improve the quality of life for patients and their caregivers.

5 **From These Resources Come Unity**  
Resources exist in the community for people with dementia and their caregivers and are important elements to quality care.

According to Catherine Rydell (2002) of the American Academy of Neurology, “Clinicians may make a difference in the quality of life of patients with AD if they follow guideline recommendations.” But the first step in making a difference is to inform the public, especially the clinicians who care for people with AD, about these guidelines.

We are optimistic about the future of those who may face and are already facing AD. We believe that adhering to the five basic principles just stated can improve the life of those living with AD. And here’s what we consider the best part yet: research findings suggest that it is never too late to get started.

**How to Use This Book**

In order to understand the changes that take place in a person with AD, a solid understanding of the biological processes that cause the disease is essential. Chapter 2 explains different types of dementia, including AD, and chapter 3 details the medical causes and risk factors for AD, while providing some historical background on how the disease was discovered and where we are currently in terms of understanding AD. Chapter 4 highlights definite symptoms of AD. Chapter 5 outlines new methods of diagnosis. Chapter 6 relays the progression of AD to give an idea of what to expect once a diagnosis has been made, and chapter 7 discusses prevention and treatments, both those that are available and those whose approval is pending. The final four chapters offer a step-by-step guide to caring for persons with Alzheimer’s. To conclude, we
offer a list of resources to tap into that can facilitate readers efforts and increase their knowledge of Alzheimer’s.

This book offers direction based on our understanding and experience as health care providers and on the experiences of other physicians and caregivers who work with people with AD. But from time to time, people will need to consult competent professionals for specific advice about medical, legal, and financial matters. Also remember that a local Alzheimer’s Association chapter or area agency on aging should be able to offer a referral to professionals with a proven track record.

Our hope is that people will use this book as a reliable resource as they care for a patient or a loved one. AD has many challenges, but, with a positive outlook and the tools advanced in this book, there is promise of a brighter future.