

## Chapter 1

# The Facts on Alzheimer's Disease

### *In This Chapter*

- ▶ Defining Alzheimer's Disease
- ▶ Finding out about Alzheimer's Disease

The last time you visited your elderly mother, she seemed confused and disoriented. She kept asking the same question over and over again and couldn't remember that you'd already given her the answer a dozen times. She laughed uproariously over something you said that wasn't meant to be funny and spent a good deal of your visit staring into space with a blank expression in her eyes. When you got ready to leave, she became quite upset because she couldn't find her purse and accused you of hiding it. None of these behaviors is typical for her, and you can't help wondering — could this be Alzheimer's Disease?

It could be.

An estimated 4 million people are living with Alzheimer's Disease (AD) in America today, with approximately 370,000 new cases diagnosed every year. The incidence of the disease rises dramatically with age, from 3 percent affected in the 65 to 74 year age range all the way up to 47 percent affected in the 85 and older age range. AD patients live anywhere from 5 to 20 years after their diagnosis, and their inability to care for themselves grows more dramatic as the disease progresses, creating profound implications for their families and healthcare providers.

AD causes fewer than 50,000 deaths annually, making it only the eighth leading cause of death. But its impact on families during the caregiving years is overwhelming. Particularly worrisome is that, as America's Baby Boomer population ages, experts are predicting an epidemic of Alzheimer's Disease; that makes continued research even more crucial.

This book is intended to serve as a resource guide to anyone who has a family member living with Alzheimer's Disease. Whether you're a caregiver, a friend, or a family member of an AD patient simply looking for additional information, *Alzheimer's For Dummies* is a great place to start.

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### *Defining Alzheimer's Disease*

AD is a form of dementia. Although all AD patients have dementia, not all dementia patients have Alzheimer's Disease. The Alzheimer's Association defines Alzheimer's Disease as "an irreversible, progressive brain disease that slowly destroys memory and thinking skills, eventually even the ability to carry out the simplest tasks." AD is a fatal disease, ending inevitably in death.

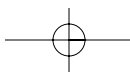
Alzheimer's Disease was named after a German physician, Alois Alzheimer, who first identified the condition in 1906 when he performed an autopsy on the brain of a woman who'd been suffering severe memory loss and confusion for years. He observed plaques and neurofibrillary tangles in the woman's brain tissue and correctly hypothesized that these abnormal deposits were responsible for the patient's loss of memory and other cognitive problems. To this day, AD can only be diagnosed with 100 percent accuracy through an autopsy that reveals the presence of the characteristic plaques and tangles. However, a comprehensive examination and good work-up do provide a reliable diagnosis with greater than 90 percent accuracy.

Abnormal deposits of specific proteins inside the brain disrupt normal brain function and cause the cognitive and functional problems typically associated with AD. Eventually, as the deposits spread throughout the brain, brain tissue starts dying, which leads to further cognitive impairment. The resulting brain shrinkage can be seen in CT scans and MRIs. Current research is focused on trying to determine what causes these deposits and is looking for ways to prevent or reverse them before they cause permanent brain damage.

Healthcare professionals are already sounding the alarm in the halls of Congress, warning that many more resources must be devoted to Alzheimer's Disease research to avoid a catastrophe in the not-too-distant future. The National Institutes of Health and the National Institute on Aging, both agencies of the federal government, are partnering with various universities and research facilities in a concerted effort to foster the search for answers, and perhaps even to find a cure or a preventive agent like a vaccine. Various advocacy groups are calling for national programs to offer training and support for the family caregivers who provide 75 percent of the care for Alzheimer's patients.

Although these efforts are much needed, probably the only things you want right now are answers to some of the following questions: How is Alzheimer's Disease going to affect me, my loved one, and the rest of my family? What can I do to make the experience as positive and painless as possible? Where can I go to get help?

We hope that this book helps you answer these questions.



## *Busting the Myths About AD*

The preceding section, “Defining Alzheimer’s Disease,” talks about what Alzheimer’s Disease is. Now, allow us to go over what it isn’t. Alzheimer’s Disease is *not*:

- ✓ Curable
- ✓ Contagious
- ✓ A natural part of the aging process
- ✓ Something you get from using deodorant or cooking in aluminum pans
- ✓ Inevitable if you live long enough

Although certain familial forms of Alzheimer’s Disease do run in families, these forms are extremely rare, accounting for less than 5 percent of all cases. So just because your mother or your brother got Alzheimer’s Disease doesn’t automatically mean that you’re going to get it as well.

No test can predict whether you’ll get Alzheimer’s Disease unless you have the very rare inherited form of AD. A blood test exists that can tell you whether you have a certain form of a cholesterol-carrying protein associated with a higher incidence of Alzheimer’s Disease, but that’s all that it can tell you. The test can’t tell you whether you’ll actually develop the condition because at least 50 percent of the people who have the risk factor never actually get AD.

For ethical reasons, healthcare professionals advise against taking this blood test or undergoing other genetic testing because they want to spare their patients unnecessary worry about something that’ll probably never happen even if the tests do come out positive. They also recommend against testing because if a person does find that he or she has inherited the gene or the risk factor, this information may negatively impact the person’s ability to get health insurance and long-term care coverage.

## *Looking at Symptoms and Causes*

Doctors and researchers still aren’t sure exactly what triggers Alzheimer’s Disease, but the symptoms are all too familiar. Part I of this book looks at current theories about causes and reviews the range of symptoms that may be present at each stage of the disease. You can also find information to help you decide whether to take your loved one to a doctor for testing.

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As we mention earlier, Alzheimer's Disease has no method of diagnosis that's 100 percent accurate (other than an autopsy at death). But the range of diagnostic tools is so good that most doctors can now diagnose Alzheimer's Disease with about 90 percent certainty. The results of a battery of workups — a physical exam, lab tests, imaging, and evaluations of thinking, memory, and day-to-day functioning — are used to determine the likelihood of Alzheimer's Disease.

### *Discovering Treatment Options*

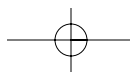
Just four drugs are FDA approved for the treatment of Alzheimer's Disease. As we discuss in Part II, the standard of treatment calls for the administration of one of the three drugs still in use, along with a recommended 2000 I.U. of vitamin E daily. Depending upon your loved one's condition, additional medications may be used to treat other behavioral symptoms of AD that can occur at any point in the course of the disease. If your loved one has an underlying condition like diabetes or cardiovascular disease, he may have to take additional medications for those conditions as well. Your doctor will work with you and your loved one to determine which medications and treatment options are best suited to your particular case.

### *Tackling Financial and Legal Issues*

A diagnosis of AD requires some thoughtful planning from families so that they can manage the complex legal and financial issues that will crop up as their loved one's capabilities diminish. Make your legal and financial decisions as soon as possible, and put plans in place before your loved one becomes incapacitated; otherwise, you may have a court peering over your shoulder every time you try to pay a bill or shift funds to cover expenses. Part III presents practical tips that could save your family thousands of dollars and hours of time.

### *Making Medical Decisions and Providing Care*

If you don't have a medical background, accepting the responsibility for making medical decisions for your loved one can be a daunting task. You can find out how to determine whether your loved one is receiving the optimum care by comparing the treatments he or she is getting to the Alzheimer's Disease Standard of Care. You'll also gain insight into the process that doctors follow to make a diagnosis of Alzheimer's Disease.



If your family is like most families, you'll opt to provide in-home care for your loved one for as long as possible, particularly in the early, more manageable, stages of the disease. Part III also discusses what care options are available in most communities along with a comparison of the cost, benefits, advantages, and disadvantages of each. You can discover how to find good caregivers and how to share the caregiving burden among various family members. You also find tips for juggling work and family with the responsibilities of caregiving.

## *Finding Respite*

Even if you're Superwoman (or Superman), you need a break from your caregiving chores sometimes. Caregiving is demanding work. Remember to schedule regular breaks to keep yourself from burning out. In Part IV, you can find lots of creative ideas for relaxing and taking time off that are both time and cost effective. You can find out how to take good care of yourself even as you provide care for your loved one.

## *What Should I Do Now?*

Losing someone you love is never easy, but losing a loved one to Alzheimer's Disease seems particularly cruel. People recognize each other in so many ways — by voice, by a glance or gesture, by a familiar and comforting touch. But the glue that truly binds loved ones to each other is their shared memories.

Alzheimer's robs all of these. It's a thorough and impartial thief that steals away the landmarks of your most cherished relationships and leaves you lost. It takes mothers, fathers, husbands, wives, sisters, brothers, grandparents, aunts, uncles, and beloved friends and turns them into strangers. And it does so ever so slowly, by agonizing inches and degrees.

In a recent interview, Nancy Reagan simply and eloquently called Alzheimer's Disease "the long goodbye." Anyone whose life has ever been touched by Alzheimer's knows instantly what she means. The person you love is there in front of you but isn't there. You can touch them, but not reach them. Like so many other grieving husbands and wives before her, Nancy Reagan has watched as Alzheimer's silenced her beloved husband, Ronald Reagan, the former President we called "The Great Communicator."

Although researchers have come a long way in their search for the cause of Alzheimer's Disease, doctors still don't have a complete answer. They've identified anomalies in the brains of Alzheimer's victims but don't know what causes them or how to prevent them. Some effective treatments have been developed, but most people with AD never get the opportunity to try one of

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these medications, or if they do, they only stay on the drug for a short period of time because most physicians misunderstand what the drugs are capable of doing. Unlike some other diseases that may strike and kill relatively quickly, AD allows its victims to live for 4 to 8 years after diagnosis, and cases are reported of individuals living as long as 20 years in a completely dependent state. This obviously creates a tremendous strain on the family that is caring for an Alzheimer's patient.

Families with an AD patient have hundreds of questions, as do AD patients themselves. What causes Alzheimer's Disease? Can it be cured? Is it hereditary or contagious? What are the best treatments?

Although not every question can be easily answered, *Alzheimer's For Dummies* gives you the latest and most up-to-date information available to help you make informed decisions about medical care, prescriptions, care options, and legal and financial issues. And if you can't find the answer in these pages, we'll show you some Internet resources that can point you in the right direction.