

WHEN ALZHEIMER'S DISEASE STRIKES

Chapter 1: HOW BIG A PROBLEM IS ALZHEIMER'S DISEASE?

According to the latest estimates, approximately four million people in the United States suffer from Alzheimer's disease. If we assume that each of these has four close family members (spouse, children, siblings), the disease actually affects some 20 million people directly, and this number does not include friends who may feel deeply for the person and his or her family. In fact, a survey in the early 1990s found that 37 million Americans said they knew someone with Alzheimer's. When Alzheimer's disease strikes a member of a religious congregation, the number of caring people touched by the illness is likely to increase even more.

These numbers are striking enough, but a glance at the shifting age patterns of the United States population as a whole prompts even deeper concern. From about 4 percent of the population at the beginning of the 20th century, the number of Americans 65 and older grew to around 14 percent by its close—from 3 million to almost 40 million (more than the entire population of Canada!). When the Baby Boomers (the 76 million Americans born between 1946 and 1964, who make up slightly more than one-quarter of the current U.S. population) start reaching 65 in 2011, the number of older Americans will surge even more markedly, growing to as many as perhaps 70 million or more by 2040, almost 25 percent of the projected total population. The fastest-growing segment of the United States population already comprises those 85 and older, who are 10 percent of the older population today but are expected to reach 20 million and make up as much as 30 percent of all elderly by the middle of this century. Moving even farther along the life span, the number of centenarians in this country quintupled to almost 70,000 between 1980 and today, doubling in the 1990s alone. By 2050 the U.S. Census Bureau projects that as many as 1.1 million people in this country are likely to be over 100!

Why are these numbers so significant? Carl Eisdorfer, an internationally recognized geriatric psychiatrist and one of the founders of the organization now known as the Alzheimer's Association, estimates that the need for care doubles every 5 years a person lives past 65. A sizable portion of that care goes to those suffering from Alzheimer's disease and other dementias because the illness affects primarily older people, although there is a rare form called "early-onset Alzheimer's" that occurs in only five to ten percent of all cases, in which symptoms begin to appear as early as 40. The incidence of Alzheimer's disease also doubles every 5 years beyond 65. Indeed, the 1-in-10 likelihood of developing Alzheimer's at 65 may be as high as 1 in 5 by the time a person reaches 75 and nearly 1 in 2 by age 85 (and remember that those over 85 constitute the most rapidly growing segment of our population). These facts have led experts to estimate that without the cure for which we are all fervently praying, the number of people with Alzheimer's in the United States will approach 6 million by the end of this decade and 14 million by the middle of the century.

Many religious congregations have an even higher percentage of older members than the population in general. For example, 67 percent of the members of the Presbyterian Church (USA) are over the age of 45, 57 percent are over 50, and 35 percent are 65 or older. The median age of members is 54, whereas the median age for the U.S. population as a whole is about 36. This is a trend that is seen across other such denominations, with most reporting that at least 20 to 25 percent of their members are 65 and older. Thus it is especially critical that clergy and laypeople of all faiths learn as much as they can about Alzheimer's disease.

Chapter 2: WHAT IS ALZHEIMER'S DISEASE?

Alzheimer's disease is precisely that—a disease with its own distinctive effect on a person's body and behavior. Named after the German neuropathologist who in 1906 first described the changes the illness

causes in a person's brain, Alzheimer's disease is a progressive, irreversible, degenerative illness that destroys the brain, leading to a condition known as "dementia."

Alzheimer's disease is the most common form of dementia occurring in the U.S. today. Dementia means literally "out of one's mind," but the term has a special medical usage: It does not mean "crazy" in normal parlance but rather denotes a loss or impairment of mental capacity serious enough to affect a person's ability to function normally. The condition is marked by specific symptoms that distinguish it clearly, which will be described below. Although a number of dementias exist (not all associated with aging), this book will concentrate on Alzheimer's disease, which comprises the vast majority of cases. Most of what will be said, however, applies with minor variations to the other dementias.

Let me make a very important point here, one that must be clearly understood: Alzheimer's disease and related dementias are not the result of simply "getting old," as some people have come to fear, though the incidence does rise with age. Nor are they in any sense "normal" aging. In fact, if anyone you know begins to demonstrate the symptoms described below, that person should have immediate medical attention, regardless of age. It is an extremely dangerous though still widespread myth that growing older automatically leads to what used to be called "senility," which is often attributed to "hardening of the arteries." It is very important to remember that some 20 to 30 percent of dementias are caused by treatable conditions (e.g., depression, dehydration, malnutrition, infection, or problems with prescription medication), and thus they are partially or completely reversible. Therefore if a loved one of any age begins to show signs of confusion and/or memory loss, get him or her to a competent physician for testing and diagnosis at once.

Despite major advances in Alzheimer's disease research, the cause of the illness remains unknown. A number of theories have been advanced and are constantly being tested. Researchers are closer than ever before to identifying what in all likelihood will turn out to be not the cause of Alzheimer's but many factors that together contribute to the appearance of the disease. The ones currently considered to be the most likely are genetic (you will hear quite a bit about the "APOE gene"), environmental (such as head trauma at any age, even much earlier in life), and what I will call "internal" (increases in free radicals in the brain, high blood cholesterol levels, high blood pressure and heart disease, and the like).

A recent development that is somewhat confusing merits mention here in passing. In the late 1990s, researchers and physicians began to diagnose and discuss mild cognitive impairment (MCI), which some authorities now suggest may be a precursor to Alzheimer's disease (although others argue it is simply very early Alzheimer's). In this condition, the person has persistent memory problems. MCI differs from normal age-related memory change, however, in that the loss is greater than expected, and from Alzheimer's in that the person with MCI does not exhibit other losses typical of dementia, such as confusion, problems with attention, and language difficulties.

Some experts estimate that more than 80 percent of people with mild cognitive impairment develop Alzheimer's disease within 10 years at a rate of 10-15 percent of them a year. This has led to the conclusion that MCI is really early Alzheimer's disease, rather than a separate, distinct condition. Whatever the outcome of this debate, the concept of MCI is important because it has led to studies designed to learn if early diagnosis and treatment can prevent or slow further memory loss, including the development of Alzheimer's disease. You may want to keep your eyes and ears open for more information about this matter, especially if the person you are caring for is in the early stages of Alzheimer's.