# HELP! SOMEONE I LOVE HAS ALZHEIMER'S

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To our parents, Joe and Glen Koon, and W. D. "Buddy" and Floye Howe, with appreciation for the love and encouragement they've given us over the years

### INTRODUCTION

Certain words can strike terror in our hearts. "Cancer," for instance. Or "death," "root canal," "amputate." Words have power.

One of the most feared phrases in our vocabulary is "Alzheimer's disease." This diagnosis has the power to leave us paralyzed with disbelief and dread, whether it relates to us or to someone we love.

Outside the perspective of God's perfect will, we are justified in fearing this condition. Even before the diagnosis, Alzheimer's disease has already begun to erode the personality, function, and intellect of its victims. Insidious in its progression, it robs people of their lives and dignity, leaving grief and agony in its wake.

I hate Alzheimer's disease.

Only *within* the perspective of God's will can we begin to make sense of it. Our perception improves when we view this disease through a

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spiritual lens. No, dementia sufferers can't rise above dementia by the power of their wills. No, there is nothing the family can do to "make it all go away." But yes, we *can* find peace, joy, abiding love, and even humor along the journey.

I pray that these pages will serve to inform, encourage, and comfort you if someone you love has received this dreaded diagnosis.

### Let Me Walk with You

This book approaches Alzheimer's disease from three perspectives: the physiological (theory and treatment), the practical (helpful suggestions for caregivers), and the spiritual (meditations upon God's goodness in the face of adversity). Professional and personal experience motivates my desire to help in any way I can.

#### A Page from My Own Story

My life and the lives of my family were forever changed in 1963 when my father was diagnosed with two brain tumors. The surgery to remove them left him severely impaired. My bright, robust, funny, talented, good-looking, gregarious father now had to be led to a chair, where he simply sat, staring. A knitted cap covered his healing scars.

The scars on the inside, however, proved harder to heal. Yet, incredibly, he regained more function than the doctors predicted. Though legally blind, some of his vision returned. Though halting in his movements, he was able to again walk unassisted. Though the notes on the musical score were blurry and elusive, he was able to return to his band room as the much-loved director he'd been before the surgery.

Understanding that Daddy would never be exactly as he was before, we did return to some semblance of normalcy. My mother became the reluctant head of the household, rising to every challenge. She was such a trooper that we never realized her heart was broken. We were just happy to have Daddy home. We didn't understand that, in a way, Mom had lost the husband of her dreams and that her heart was filled with fear, grief, and sorrow as she bravely struggled to care for him and her three children.

Daddy's decline continued, however. His field of vision diminished until he could see only a pinpoint, and even that was blurred by double vision. This vision loss decreased his overall function. But the truly damaging change was in his thinking.

Dementia increasingly undermined his mental capacity—and his pizzazz. The ongoing atrophy of his brain (along with the original damage from the surgeries) is thought to be the cause of his dementia. Though he doesn't have Alzheimer's disease, his dementia has been devastating nonetheless. By God's grace, I don't think he realizes it, even now. As we have watched him slowly fade away, he remains happy and sweet, appreciative and loving. He couldn't tell what day it is if his life depended on it. Yet he still loves his children and adores his wife. And for the past five decades, she's continued to care for him—lovingly, capably, and continuously.

A few years ago, however, we started noticing changes in Mom's personality, level of function, and ability to maintain the household. Concerned, I took her to the doctor, where she was eventually diagnosed with the early stages of Alzheimer's disease. My brother and I realized that our parents could not continue living by themselves and we had to make some difficult decisions regarding their welfare.

For our family, the solution was assisted living, where Mom still looks after Daddy. It's her shoulder he holds onto to walk to the dining room. She's his faithful advocate. She's the one who's there, twenty-four hours a day, to either listen to him repeat the same words, questions, or phrases, or to cope with the silence of a husband so mentally locked-in that he doesn't speak for hours.

For almost as long as I can remember, Daddy's been this way. And for as long as I can remember, my mom's been able to handle anything! So it's harder to respond to her loss of function than it has been with Daddy.

Why am I telling you this? Because it's important for you to know that I do not write from an untouched, academic viewpoint. I'm writing this book as a person whose life has been dramatically altered by this disease for decades.

Suffering Is Biblical

For Christians, our joy in Christ is not dependent upon a happy, trouble-free life. In fact, God's Word warns us that our lives *will* be touched by suffering, trials, and tribulations.

For instance, in John 16:33 Christ says,

In the world you will have tribulation. But take heart; I have overcome the world.

The victory already belongs to him ... and to us.

Repeatedly, he assures us that our reward and ultimate joy do not reside in this world, but in the next. John 14:1-4 explains that Christ has gone ahead of us, to prepare a place for us where we will dwell with him forever. He is our refuge, our joy, our resting place. It is in the shadow of his sheltering wings that we will find ultimate peace, safety, and joy. In heaven, there will be no tears, no sorrow, no pain, no suffering—and no dementia.

But we're obviously not in heaven now. Therefore, we need to learn not how to *escape* from suffering and pain, but how to honor God in the midst of it.

We know this is possible because of the apostle Paul's remarkable example. His life as a believer was far from idyllic. He suffered multiple floggings, beatings, shipwrecks, hunger and thirst, imprisonments and persecution. Yet Paul was the one who said,

For I have learned in whatever situation I am to be content. I know how to be brought low, and I know how to abound. In any and every circumstance, I have learned the secret of facing plenty and hunger, abundance and need. I can do all things through him who strengthens me. (Philippians 4:11-13)

Developing and maintaining this godly

perspective helps us persevere through the trials of Alzheimer's disease—or *any* adversity. The same God who strengthened Paul in every circumstance stands ready to do the same for us. His presence is the only cure for anything that ails us—even Alzheimer's disease. He may not take away the condition, but he'll see us through the experience. If we learn to keep our eyes focused upon him, we can travel this journey with faith, joy, love ... and hope.

## Knowledge Is Power

One of the most effective ways of coping with adversity is education. Knowledge really is power! It provides the foundation to attack our problems, bolstering us with the assurance that we're doing all we can to bring calm, sensible management, and comfort to the situation. So, the more we understand about our adversary, Alzheimer's disease, the better we'll be able to predict what's coming and respond appropriately when it comes. Learning everything you can about Alzheimer's disease will make you more effective in caring for your loved one.

The fact that you're reading this book indicates that you're already on this positive, constructive path of learning about Alzheimer's disease. I hope to improve your understanding in the following pages.

#### What Is Alzheimer's Disease?

Dementia is a condition which causes changes in mental function. It affects thinking, reasoning, memory, personality, mood, and behavior. Almost everyone experiences memory impairment with age, but those with dementia experience losses severe enough to interfere with *the ability to function in life*.

Alzheimer's disease, frequently referred to as AD, is the most common form of dementia, but there are more than fifty others. For the purpose of this book, I will refer to all dementias as Alzheimer's disease, since the practical solutions and guidelines are similar, regardless of the diagnosis.

Some people are reluctant to seek medical advice when they suspect a problem in their thinking processes—afraid to discover that they have Alzheimer's disease. But it's very important to understand that many other medical problems, *some reversible*, can cause symptoms of dementia. These other conditions include meningitis, Lyme disease, metabolic problems, medication interactions, exposure to heavy metals or pesticides, alcohol abuse, and hypoxia (a state of oxygen deficiency). Sometimes, mental disorders, such as bipolar disorder or schizophrenia, can cause symptoms that respond well to medication. There's no specific test for AD, so the diagnosis is generally made by ruling out other causes and interpreting scores from cognitive evaluations (measurements of the mind's ability to think, perceive, and know). That's why I urge you to seek medical attention if you suspect a problem with your loved one.

But back to our original question: What is Alzheimer's disease? It is a brain disorder resulting in a progressive decline in intellectual and social skills, interfering with a patient's ability to perform the activities of daily life and to interact meaningfully with others.

It is more than simple forgetfulness, which is considered a normal characteristic of aging. AD symptoms are much more severe and incapacitating. The most likely cause for the vast majority of sufferers consists of aging, lifestyle, and/or environmental factors.

Although the causes of Alzheimer's are not definitive, its effect on the brain is well known and devastating. Alzheimer's disease kills brain cells and disables the connections between the remaining cells. When doctors examine the brain of an AD sufferer after death, they find that it is significantly smaller than a normal brain, and displays the two hallmarks of AD: *plaques*— protein clumps thought to kill brain cells and interfere with cell-to-cell communication in the brain; and *tangles*—abnormal fibers of protein in the brain which do not function properly; they can't carry nutrients and other essential materials to brain cells like normal fibers.

Warning Signs of Alzheimer's Disease

So when is the problem a result of normal aging and forgetfulness, and when is it time to see your doctor? The following are ten warning signs provided by the Alzheimer's Association:

- » Memory loss that disrupts daily life. One of the most common signs of AD is memory loss, especially forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; and relying on memory aids or family members for things they used to handle on their own.
- Challenges in planning or solving problems.
  Some people may experience changes in their ability to develop and follow a plan or

work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

- » Difficulty completing familiar tasks at home, at work, or at leisure. People with AD often find it hard to complete daily tasks. They may have trouble driving to a familiar location, managing a budget at work, or remembering the rules of a favorite game.
- » Confusion with time or place. People with AD can lose track of dates, seasons, and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they forget where they are or how they got there.
- » Trouble understanding visual images and spatial relationships. For some people, having vision problems is a sign of AD. They may have difficulty reading, judging distances, and determining color or contrast. In terms of perception, they may pass a mirror and think that others are in the room, not realizing that they are the ones in the mirror.
- » New problems with words in speaking or

*writing.* People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue, or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word, or call things by the wrong name.

- » *Misplacing things and losing the ability to retrace steps.* People with AD may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes they accuse others of stealing. This may occur more frequently over time.
- » Decreased or poor judgment. People with AD may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean.
- » Withdrawal from work or social activities. Those with AD may start to remove themselves from hobbies, social activities, work projects, or sports. They may have trouble keeping up with a favorite sports team or remembering

how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced.

» Changes in mood and personality. The mood and personalities of people with AD can change. They can become confused, suspicious, depressed, fearful, or anxious. They may be easily upset at home, at work, with friends, or in places where they are out of their comfort zones.<sup>1</sup>

If your loved one exhibits any of these behaviors, it's time to seek a medical evaluation and diagnosis.

### Diagnosis

In diagnosing AD, the doctor should first conduct a thorough medical history and physical exam to rule out problems caused by other conditions or medications. He or she may then administer cognitive or mental-status testing, typically asking your loved one to perform a combination of the following:

- » Draw a clock face depicting a specific time
- » Name the current date and time

- » Remember three words after several other exercises
- » Name ten items in a given category, such as animals or fruits
- » Count backwards from 100 by sevens
- » Follow a multiple-step set of instructions

The doctor will probably perform a standard neurological evaluation to assess balance, reflexes, and sensory function. If there are signs of cognitive impairment without a clear cause, the doctor may want additional tests.

The first testing options are simple blood and urine tests. Another is a spinal tap. Your doctor may also order one or more brain imaging scans, such as CT, MRI or PET scans.

Historically, brain imaging has been used to rule out other causes of dementia, such as stroke or tumor, leaving AD as the "default" diagnosis when no other cause is detected. Clinical trials and ongoing research are underway that may lead to a more definitive diagnosis, earlier intervention, and the hope of reversing or slowing the progression of the disease.