NAVIGATING ALZHEIMER'S

12 Truths about Caring for Your Loved One

MARY K. DOYLE

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in extenso

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Like sunshine
on an overcast day,
rays of the man I knew
peek through the clouds
leaving me longing for more.

Foreword by Herbert Sohn, MD

At last we have a book that will be truly valuable for anyone taking on the task of providing primary care to an individual with Alzheimer's disease.

Mary Doyle is not only an excellent writer but also has had tremendous experience taking care of her husband with Alzheimer's for many years. Being able to put such practical experience into language medical lay people can easily grasp is an art, and she has certainly perfected that art.

Her book not only explains the unique problems connected with the disease but also gives the reader real insights into what can be done to help both the individuals suffering from the disease and their volunteer caregivers.

It has been known for many years that one of the major causes of depression among people who take care of loved ones with Alzheimer's is that they are not prepared for the type and amount of work involved. Mary Doyle has given them a superb guide, and I congratulate her on the excellence of her endeavor.

Dr. Herbert Sohn is a member of the board of directors of Healing Our Veterans, which works with veterans with Alzheimer's, PTSD, and effects of strokes. His credentials include FACS (Fellow of the American College of Surgeons) and FACLM (Fellow of the American College of Legal Medicine). Dr. Sohn is a Past President of the American Association of Clinical Urologists and Past Vice-Chair of the Board of Trustees, University of Health Sciences, Chicago Medical School (now Rosalind Franklin University). He is also an attorney and a urologist in practice for over 50 years.

Setting Sail for the High Seas

Early in the disease, when I told someone that my husband had Alzheimer's, I got that deer-in-the-headlights look, the one that signals something terrible is about to happen and there is nothing you can do to stop it. There was no hiding their concern and sorrow for what we were about to face.

Caring for a loved one with Alzheimer's is like navigating a voyage on the high seas. The course offers an unpredictable combination of magnificent and turbulent experiences. Caregiver survival depends on steady footing, dependable support, and a lot of prayer.

As primary caregivers to someone with Alzheimer's, our responsibilities are at their maximum. Our undivided attention is needed every second of every day. Our loved ones' physical, emotional, and mental needs are in our hands. Unlike caring for children, who also require undivided attention, the journey of Alzheimer's is one of decline rather than growth, increasing dependence rather than independence. We must think for our loved ones in every way, and we realize that care will extend for the rest of their lives here on earth. Such intense care is wearing on our emotional and physical health as few other caregiving roles are.

But there is so much more to our experience than this. We also encounter grace-filled moments. The woman before us is the mother who nurtured, worried about, and prayed for us. This is the sibling we shared secrets with, the husband who was "our everything." Even in the late stages of our loved ones' Alzheimer's, we caregivers experience fragments of the person we knew. We hear stories from the past that we've long forgotten, or never heard, and share tender, loving moments meant only for us.

The care required is intimate and soulful. It's heart-wrenching and heart-warming. People with Alzheimer's are often agitated, frustrated, and confused. But they also can be quite sweet, innocent, and profoundly appreciative of our presence.

My intention for this book is to offer solid information, understanding, compassion, and resources. Each chapter begins with a title/statement, an example of what that statement looks like in action, and what I learned from that aspect of caring for someone with Alzheimer's. Most chapters include bullet points and each ends with a short list of practical suggestions.

I have no medical background. I am a professional writer with a Master's Degree in Pastoral Theology. I write from experience. My husband, Marshall, has Alzheimer's. I cared for him myself at home for the first nine years of his illness, called in caregiving assistance the tenth year, and I have now moved him to an assisted living home exclusively for memory care.

Our situation is different than most because Marshall was an entertainer his entire adult life. In some ways his past profession makes the journey easier. In other ways it makes it more difficult.

Marshall, at least at this point, doesn't have the fear of strangers most people with Alzheimer's do. For them, when they walk into a room of people they do not know it is as if they were transplanted to another country where nothing is familiar. In contrast, Marshall often assumes these strangers are fans and so is less frightened of them than he might be otherwise. Being center stage is familiar to him, something few people with Alzheimer's feel.

Marshall can't hold much of a conversation anymore, but he has performed magic since he was a child and still can do some tricks. His playful manner and magic skills continue to spark laughter in the people around him. This allows him to connect with others in a meaningful and positive way.

Our large family and a small circle of friends see him often, but we ask that others, beyond those closest to him, respect his privacy. It is best for his health and safety that fans and other more casual friends do not visit. He loved and appreciated them all, but at this time the visits are too wearing on him.

Basically, though, our story is similar to most. Sprinkles of our personal experiences are scattered throughout this book. I share these moments when I think they offer something for you to relate to. If nothing else, I hope they demonstrate that you are not alone.

I encourage you to call on family, friends, your church or congregation, and public agencies for help. We caregivers of those with Alzheimer's cannot, and need not, do it alone. It truly takes a village to care for someone with Alzheimer's. There are 5 million and counting who have the disease in the United States and Canada alone, and each person requires at least three to four people to care for them. So the number of people necessary to provide care for all our loved ones is extensive.

Reach out to other caregivers. Talk with people who know what you are going through. You will find a list of organizations in the resource section of this book that can help you find support groups.

Marshall's outstanding neurologist calls Alzheimer's "The caregivers disease" because it is so exhausting for the loving friends and family who care for those with Alzheimer's, often for years or even decades. In addition, often when one family member—a spouse, one of the children, or a close friend—is the primary caregiver, it can result in anger and resentment, power struggles, changes in dynamics of relationships, and loss of the caregiver's own independence. For these reasons, the illness necessitates that we caregivers count on other people to assist us as we assist our loved ones. It forces us to acknowledge that we human beings need one another and truly are all connected, one person to the next.

1. Alzheimer’s Is Not a Part of Normal Aging

WHAT IT’S LIKE

Your husband went out to run some routine errands and said he would be back in an hour. Four hours later he calls from a clerk’s phone at a convenience store across town. He doesn’t know where he’s been or where he is. This is not the first time, and it will surely not be the last.

WHAT I LEARNED

If we suspect something is wrong with a loved one's memory, we need to arrange a medical evaluation right away. They will be reluctant to go, but early intervention can make a significant difference in how things progress from then on.

We are our brother's keeper, and this statement is never truer than when someone we love has Alzheimer's. We are their advocate, guardian, caregiver, and friend, and successfully filling these roles is vitally important—from the first suspicions of the disease.

At first we know something is wrong, but we don't know exactly what it is. Our mother seems more distracted, forgetful, agitated, and confused. She is short-tempered and argumentative. She may even be sexually inappropriate. Basically, she just doesn't act like the person we knew. We wonder if it is normal aging or an indication that something has changed in our relationship or in her health. Our worst fear is that it has something to do with her loss of memory or, even worse, an early sign of Alzheimer's.

The suspicion of any memory disease is terrifying. So many parts of our relationship are threatened. Not only is the present day in jeopardy, but our entire future with them is too. Where do we even start to find answers? Whom do we turn to for help?

We begin by considering the type and extent of symptoms we are noticing. Some physical illnesses can manifest changes in personality as much as mental illnesses do. When we do not feel well it takes a toll on our emotional and mental well-being too. Initially, it may be difficult to discern if this is merely a temporary condition or something more ominous.

We also need to analyze the extent of the memory issues. It's normal to occasionally forget a name, miss an appointment, misplace a cell phone, or forget to pay a bill. We all do these things, especially if we are busy, distracted, or constantly multi-tasking.

If these episodes are happening often, however, check with a physician. Our loved ones aren't likely to recognize the state of their current condition or openly admit to any deficit. They may minimize their problems out of fear and an understandable lack of objectivity. A good physical exam by an observant physician—especially one skilled in dealing with the elderly—can rule out common causes for temporary dementia, such as a thyroid imbalance, alcohol abuse, or conflict with a medication.

If there is no apparent cause, a basic memory screening will be given. Further testing may include neuropsychological tests and a brain scan, which can give a more accurate diagnosis. Newer tests, such as analyzing saliva, blood, or cerebral fluid, are helpful in forming a correct diagnosis, although the only way to absolutely confirm Alzheimer's disease at this point is by examining the brain after death.

In any event, although there is no known cure or irrefutable diagnosis, early intervention can help manage, and possibly slow, the progression of Alzheimer's symptoms. Nerve cells in the brain begin dying long before symptoms are noticeable, so the sooner treatment begins, the greater the efficacy of the long-term care for our loved ones and, ultimately, the better their quality of life—and, by extension, ours.

Even if we have long suspected that our loved ones do indeed have Alzheimer's, the final diagnosis of it is devastating. I clearly remember the day the doctors told our family that test results made it pretty clear that my husband, Marshall, had Alzheimer's disease. It had become more and more evident with each disappointing test result, but the words telling us that it was indeed true were painful to hear.

My body physically reacted to the news with a churning stomach and throbbing head. I wondered what that meant for us and our future as a family. I worried it was the end of our marriage as we knew it.

Alzheimer's certainly has changed the course of our relationship. We've met insurmountable challenges. You will too. But I guarantee you that you also will have warm, loving, and joyful times as well. You need only to keep your heart open (and get plenty of rest, which isn't easy to do if your loved one is up throughout the night).

If you suspect a problem with your loved one's memory, consider the differences between typical, age-related changes and budding signs of Alzheimer's:

DIFFERENCE BETWEEN NORMAL AGING AND ALZHEIMER'S

Typical Age-Related Changes	Signs of Alzheimer's
Missing a payment	Inability to manage a budget or balance a checkbook
Not knowing an occasional date	Rarely or never knowing the date or not knowing the season.
Occasionally losing an item	Often losing things and not being able to retrace steps
Forgetting a name but remembering it later	Forgetting the names of grandchildren or other close family members
Occasionally making bad decisions	Inability to make a decision
Slower learning process	Inability to learn new skills and information
Confusing the remote with the phone	Not recognizing the phone for what it is

WHAT CAUSES ALZHEIMER'S?

Dementia refers to a group of symptoms that include mental confusion, memory loss, disorientation, intellectual impairment, inability to learn new things, and repetition. Alzheimer's disease is a particular form of dementia that typically manifests these types of symptoms and an array of others including depression, irritability, hallucinations, and paranoia. Initially, the change in personality may be more apparent than the memory loss. It often is what family members notice first.

Alzheimer's disease is the sixth leading cause of death in the U.S. Approximately 500,000 people die each year as a result of this disease. One in three seniors dies suffering from some form of dementia.

Alzheimer's affects more than 5 million Americans and that number is expected to soar to more than 13.5 million by 2050. Most people with Alzheimer's are 65 years of age or older. The probability of developing it increases with age. The rate is higher in women, partly because women live longer.

Symptoms of Alzheimer's vary with a person's disposition, preexisting health conditions, and the advancement of the disease. The disease is irreversible and progressive. The decline may transpire over a few years or may take decades. In advanced stages, assistance is needed with bathing, dressing, toileting, and eating. In the final stages, the ability to communicate and recognize loved ones is lost and the person with the disease requires continuous care.

There remains much that is unknown about Alzheimer's and its causes. It appears to result from a combination of genetic, lifestyle, and environmental factors. Suspected risk factors include depression, high cholesterol, Type 2 diabetes, high blood pressure, and excessive weight. New studies suggest a deficiency in Vitamin

D and hearing loss may be contributing factors, and head injuries may also play a role.

The risk of developing the disease is somewhat higher if a parent or sibling has it now or had it in the past. There are mutations in three genes that increase the likelihood of getting Alzheimer's by about 5 percent. The strongest risk gene known at this time is apolipoprotein e4 (APOE e4).

The occurrence of Alzheimer's appears less often in people with higher levels of formal education. A stimulating job, mentally challenging leisure activities like reading, frequent social interactions, playing a musical instrument, and even just playing games or doing crossword puzzles may all help to prevent Alzheimer's. Studies show that healthy eating, brain and physical activity, and good heart health may slow dementia for people at risk for the disease.

Alzheimer's is believed to manifest in what are called "plaques and tangles" throughout the cortex of the brain. Plaque consists of protein fragments called beta-amyloid that build up between nerve cells. Tangles are twisted fibers of a protein called "tau" that accumulate inside cells. Both plaques and tangles destroy the ability of nerve cells to function and communicate.

From the mid-stages of Alzheimer's on, a loved one will require 24/7 attention. Supervision and cueing (prompting) are needed to keep them safe and on track. They may be able to do quite a bit for themselves for many years, as long as someone is nearby to guide them.

Some treatments and therapies are thought to help with the symptoms, making life easier for both the person with the disease and their caregivers. Medications may lessen the severity of symptoms, for at least a limited time. Behavior modification is often also effective.

Behavior modification involves changing the way a person responds to stimulus. It uses positive reinforcement, opportunities to excel, and the process of redirecting a loved one stuck on a particular thought to prevent their agitation or insistence on something from escalating.

From the time of diagnosis, I made an effort to protect Marshall's dignity and keep him socially and physically active. I closely monitored his medications, supplements, and diet. I continued to treat him respectfully as an adult, my husband, and a senior 20 years older than I am. Our doctors believe my actions contributed significantly in delaying the pace of his further deterioration. The extra effort on my part benefited him, me, and our relationship for many years.

THREE THINGS TO DO AS SOON AS YOU SUSPECT DEMENTIA

1. Don't delay talking to your physician.
2. Rule out other physical illnesses. Screen for Alzheimer's and other forms of dementia.
3. Seek ongoing neuropsychological care.