

ENDORSEMENTS

“Here is a very compelling presentation of a difficult journey. This story from the heart is a powerful and compelling book.”

—Stephen G. Post, Ph.D.
*Professor, School of Medicine,
Case Western Reserve University*

“Floyd Fought presents a refreshing and honest description of his and Wilma’s pilgrimage through the many challenges of caregiving. It is a story of love, devotion, and faith.”

—Bill E. Beckwith, Ph.D.
*Author, *Managing Your Memory: Practical
Solutions for Forgetting**

“The Rev. Floyd Fought’s story, written with candor and insight, will provide a guideline as to how to cope with the demands and ravages of Alzheimer’s. Every family confronting the demands of this illness will profit from this richly creative story.”

—Rev. Emerson S. Colaw
Retired bishop, The United Methodist Church

“Because the best ideas often come from family caregivers who are willing to try new things, these lessons, gleaned from Floyd’s experiences, are priceless for family caregivers.”

—Dotty St. Amand, M.S.W.
*Executive Director, Alvin A. Dubin Alzheimer’s
Resource Center
Fort Myers, Florida*

THE LONG
ROAD TO
GOODBYE

THE LONG
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GOODBYE
OUR JOURNEY WITH ALZHEIMER'S

FLOYD FOUGHT



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DEDICATION

This book is dedicated to our children,
Tim, Dan, Steve, and Marilyn,
whose many phone calls made the burden
lighter and the journey brighter while drawing
our family closer together though separated by
hundreds of miles—Thank you.

TABLE OF CONTENTS

Preface: A note from our daughter	xi
Acknowledgements	xv
Introduction	xvii
Chapter 1: The “A” Word; Welcome to the World of Alzheimer’s.....	19
Chapter 2: The Best Day Possible for Wilma	29
Chapter 3: The Power of Choice.....	41
Chapter 4: Forty-eight Hours a Day.....	51
Chapter 5: Helpful Hints for the Journey.....	63
Chapter 6: Resources for the Journey	79
Chapter 7: Alzheimer’s Up Close	91
Chapter 8: Keep Your Fork	105

PREFACE: A NOTE FROM OUR DAUGHTER

Recently, we moved my mother's piano from our house to my brother's home, where his three-year old daughter has become its official guardian. She makes sure that the wooden cover slips over the keys at night, and she removes the cover in the morning. This is how the piano "sleeps" and wakes up.

Mom's piano has a history. My dad scrimped and saved, then traveled miles to get Mom's piano for her when he was just a poor country preacher and their first child was on the way. It wasn't an inexpensive used upright, but a sleek piece of furniture where Mom could play hymns and classical music and give piano lessons.

The memory that I hold close is that of her lively fingers playing the "wild and wicked" notes of

THE LONG ROAD TO GOODBYE

ragtime. She would let loose, giving vent to whatever frustrations had come during her day. And there were many of those days for this mother of four, piano teacher, and pastor's wife all wrapped up in a less-than-five-foot frame.

This book was written by my dad about a time in my mom's life when the piano keys fell silent. He has lived through every word of this book in his own sturdy but tender way.

Mom's journey with Alzheimer's touched a lot of lives. As she descended into the depths of this disease, we all moved into new paths that often defied syncopation. Our feet moved where we did not expect to go. Sometimes, to our surprise, our feet could tap in rhythm to her "offbeat" tune, and we could even dance. But none of us could have known there was any kind of music for this journey had Dad not given careful attention to every ragged note of our Mom's process.

The story of this journey came out of my dad's heart in bits and pieces. At first it was something like an agonized therapy, then it became a series of vignettes that he could share with small groups. Often the response was numerous requests for him to put his stories into written form.

And so he spoke and then wrote, and he honed the stories into not only a book of useful advice but also an inspirational source book as well. It is not easy to write about Alzheimer's. It is not easy to read about it. But in these chapters can be heard the faint stanza and refrain of a syncopated score of loss,

PREFACE: A NOTE FROM OUR DAUGHTER

grief, and sadness. But then the unexpected offbeat lands on a note of surprise and joy. Let yourself feel the offbeat. You might recognize that although it is about a devastating disease, the words, the notes, the rhythm, even the offbeat, all come together as a love story.

This story is my mother's story and my dad's story, written about hope that can be found in love. While it is true that love cannot conquer every mountain, hope can still be found in the hills and valleys of a journey with Alzheimer's. It is this extraordinary love story that buoyed him up in currents of despair that often threatened to pull him under.

Alzheimer's robbed my mother of her memories. This book steals a little bit back from that ruthless thief as, in these vignettes, our memories of her live on.

Marilyn Morris

ACKNOWLEDGEMENTS

I want to offer a special word of thanks to Roger Palms, whose editorial skill organized my writings about our journey with Alzheimer's and gave birth to this book.

INTRODUCTION

In 1904, a woman died in Germany. Her physician was Dr. Alois Alzheimer. Early in his research Dr. Alzheimer had asked the woman, “What is your name?”

“Auguste,” she answered.

He asked, “What is your last name?”

“Auguste,” came her reply.

“What is your husband’s name?”

“Auguste, I think.”

So Dr. Alzheimer asked her to write her name and gave her a pen. After a few tries, Frau Auguste D. put down the pen and said softly, “I have lost myself.”

Back then the average life span was about forty-seven years. Today, the fastest growing age group is eighty-five and up, when the risk of developing

THE LONG ROAD TO GOODBYE

Alzheimer's or some form of dementia is almost 50 percent. According to one poll taken in 2006, one of the greatest fears of Americans is the fear of losing their mental capacity.

We are afraid of losing ourselves.

Chapter 1

.....

THE “A” WORD; WELCOME TO THE WORLD OF ALZHEIMER’S

Retirement came after nearly fifty years of ministry in the United Methodist Church. My wife, Wilma, and I were thrilled to move into our newly renovated home on the shore of Lake Erie. We dreamed of freedom, travel, winters in Florida, and visits with our four children. We had lived full lives, and now it was time to savor the benefits becoming to senior citizens.

We were still beginning to make plans for an exciting future when we visited a doctor in our new location, and he went over the files sent by our previous physician. He rocked us with the news that he suspected that Wilma was in the very early stages of Alzheimer’s. What was he talking about? I knew nothing about the disease. I didn’t even know how to spell it. And certainly we had no idea of the implications in the doctor’s announcement.

THE LONG ROAD TO GOODBYE

We were referred to a neurologist who confirmed the diagnosis. It was July of 1991, one month after we had retired. Having lived all our married lives in parsonages owned by the church congregations, we had just moved into the first house that we had ever owned and were anticipating the wonderful years ahead. Our journey into a happy future was suddenly thrown into confusion and chaos.

How was it that such a monstrous life-changing disease could suddenly appear out of nowhere? There was no warning pain, no unexplained illness, no dizziness or unsteadiness.

No Idea What Lay Ahead

Our first reaction was denial, followed by unbelief, and then anger. Gradually, denial was replaced by reality, unbelief was set aside by acceptance, and the anger subsided. For me, each of those steps took time, as I not only absorbed the news intellectually but also worked through its emotional impact. But neither Wilma nor I had any idea of what lay ahead of us over the next nine years.

After the diagnosis, we were referred to a neurologist who specialized in the treatment of Alzheimer's; he arranged for an MRI, an EEG, a carotid artery exam, and an appointment with a psychologist. Although Wilma was showing few outward manifestations of the disease, the end result of all the tests confirmed that Wilma was in the beginning stages of Alzheimer's. We made an appointment with the

THE "A" WORD; WELCOME TO THE WORLD OF ALZHEIMER'S

regional memory clinic to determine the level of Wilma's Alzheimer's and received their recommendation for appropriate management.

We were at the beginning of this degenerative, debilitating disease that robs its victims of every skill and ability, until there is nothing left but a breathing, noncomprehending, noncommunicating shell of a human being.

Most articles, journals, and books written about Alzheimer's describe the three stages of the disease as "early," "middle," and "late." Each stage is then described in general terms.

From my personal experience and conversations with many others, I believe that there is yet another stage, which I choose to call the "suspicion" stage. Webster defines suspicion as "an instance of suspecting something wrong without proof or on slight evidence." This describes what appears to me in hindsight to have been our situation during several years prior to the diagnosis of "early stage Alzheimer's."

At this early stage of Alzheimer's, the small changes in Wilma's personality, ability, or skill were almost imperceptible. Later on, several friends commented on Wilma's occasional out-of-character responses, such as a total lack of recall of a shared event in their lives. For them, this was a suspicion stage. Something different was occurring but what and why was unknown and often unspoken.

Wilma May Have Guessed

I now believe that Wilma may have been the first to suspect her illness, but she remained silent in her denial. She would leave her purse or pocketbook at various places. On one occasion, she left her pocketbook on the roof of the car after filling the tank with gas. It flew off as she sped down the road on her way home. We would have never found it had not a kind and honest man seen it fly off the roof of the car. He stopped by the roadside and called us so that we could retrieve it, contents intact. Another time, while traveling, she left her purse in a restaurant. We were already 200 miles down the road when we called the restaurant to ask if it was still there. A Greyhound bus delivered it to our city of destination the next day.

Leaving her purse became such a regular occurrence that it became a part of family humor. It became my responsibility to always make certain that her purse was with us as we prepared for departure.

Although they should have, these and other events like them did not raise suspicion in me about any link to disease. During our married life, Wilma had always managed our financial affairs, written most of the checks, balanced our accounts, and prepared our income tax returns. Then one day she told me that she would no longer handle the checkbook. "Fair enough," I thought; it was now my turn. So I took over writing the checks but found it impossible to figure out the balance.

THE “A” WORD; WELCOME TO THE WORLD OF ALZHEIMER’S

Finally, I called the bank to establish the balance and discovered that our account was several hundred dollars off, in our favor. Looking back, I now realize I should have suspected that something wasn’t quite right.

There are other painful recollections of this stage. I recall when long-standing relationships became difficult for Wilma. We had formed a group of friends from college, seminary, and early ministry and had managed to stay together over the next several decades. We met several times a year in each other’s homes for meals, games, shoptalk, and lots of laughter. We shared stories of births, graduations, marriages, ministry transfers, career changes, and retirement plans.

For many years, we had enjoyed these special get-togethers with friends. But then Wilma began to fret over the preparations for the next gathering. Afterward, she would tell me emphatically, “I am not going again.” When it came time for the next meeting, I made all of the arrangements. But as time went on, I found that I needed to push Wilma harder and harder. With enough persuasion on my part, and perhaps the hope that this time would be different, she would agree to go. At the end it was the same result. She found it increasingly difficult to be with the people and didn’t want to return the next time.

I can only surmise what her thinking must have been like. Over the years, our shared experiences became memories that we referenced with just a

THE LONG ROAD TO GOODBYE

simple phrase or even a word. When the reference occurred, we would burst out laughing. Now, Wilma could no longer attach the reference to the memory. An increasing fog had obscured it. Since she could no longer laugh with our friends, she either felt left out or, worse, began to believe that they were laughing at her. In retrospect, I regret the pain it must have caused her.

Wilma may have started to become suspicious when she had the incidents with her purse or the checkbook. But those things are not necessarily the forerunners of Alzheimer's. However, the combination of these events may be reason enough to at least start to wonder about changes and ask the family doctor for an opinion.

In days gone by, families and victims of this disease tended to suffer in silence. Today, it is far more likely to be discussed. Since the openness of President Ronald Reagan about his diagnosis of Alzheimer's, magazine and newspaper articles have opened our lips and allowed the "A" word to be spoken more openly. It is now easier for us to raise our suspicions when there are subtle or not-so-subtle changes in performance levels, thought processes, or social contacts. It is much easier to talk about Alzheimer's in ordinary conversation.

The Beginning of Another Kind of Journey

When I first heard our doctor say, "Onset of Alzheimer's," I did not understand the implications

THE “A” WORD; WELCOME TO THE WORLD OF ALZHEIMER’S

of what that meant. As unprepared as we were when we first heard that diagnosis, it triggered the urgent need to make many necessary adjustments for the remaining days of our lives together. It was the end of our dreams for a long, bright, and happy retirement. It was the beginning of another kind of journey that brought us, as a couple and as a family, together in what we had neither planned for nor imagined.

Our journey with Alzheimer’s was just beginning. There would be peaks, and there would be valleys. Along the way our journey brought some surprising miracles. In the months and years ahead, I would witness the destruction of everything that was the “apple of my eye” when I met Wilma in 1943. An excellent cook, she would come to a time when she could no longer follow a recipe. This person who had graduated from college with honors, who possessed a brilliant mind, was no longer able to print her own name. I watched this gifted pianist and piano teacher decline until she could not even manage a simple scale. Once she made excellent clothing choices; the day would come when she was at a total loss as to what to wear.

As the disease progressed, routine activities such as bathing, toilet functions, and coherent conversation left. In the early years of the disease, food preparation was a joint effort. But as time went on and Wilma lost her ability to prepare meals, the task became totally mine. We were spared one particular problem of turning the knobs on the kitchen stove, for when the ability to prepare food

THE LONG ROAD TO GOODBYE

ceased to exist, it seemed the entire process was lost and would never be recalled.

I watched a proud and independent woman decline to the point where she was confined to a wheelchair, with every bit of food placed on her tongue for her and every drop of liquid brought to her lips by someone other than herself. I watched a private person come to the point of requiring me or, on occasion, someone else to attend to her toilet needs and personal care.

Perhaps the most painful experience came one day when she could no longer recognize her children. It would be as though the person I married in 1946 no longer existed.

Fighting an Incoming Tide

We were often so bewildered. “What’s happening?” we would ask over and over again. And, as the losses of Wilma’s memory and skills mounted, anger would erupt and boil over into rage. We fought against the encroachment of Alzheimer’s, but to no avail. We might as well have fought against the incoming tide.

One night, well into Wilma’s years with Alzheimer’s, we were walking on the streets near our Ohio lakeside home. A single light at each intersection provided the only illumination. Our elongated shadows followed us as we approached the light and became shorter as we neared the corner. Then as we moved on, our shadows were in front of us.

THE “A” WORD; WELCOME TO THE WORLD OF ALZHEIMER’S

The poem of Robert Louis Stevenson came to mind. “I have a little shadow/ that goes in an out with me. And what can be the use of him/is more than I can see.” Those words became hauntingly real as I made the connection between our walk in the night and our walk with Alzheimer’s. I could not escape Wilma’s presence. It was as if we were mysteriously connected. Everywhere I went, she wanted to be there with me. Sometimes, when I went to another room, she would follow silently, for no other reason than just to be there.

I realized that when everything else had left her, she was determined that I was not to leave her. The persistence of this constant presence developed an unbelievable bond between us. It was a bond beyond words, since her speech pattern was by then destroyed. It was a bond beyond the physical and in the realm of the spiritual. In our marriage, two very different personalities had become one. But it took nine years with Alzheimer’s to ripen even more the love that had started fifty-seven years before.

For yet there was joy—a strange word to describe my emotions at a time like this. The apostle Peter wrote of “an indescribable joy” (see 1 Peter 1:8). An Old Testament writer said that there was a time for everything (see Ecclesiastes chapter 3). For us, there had been a time of shock, a time of bewilderment, a time of confusion, a time of loss, a time of sorrow. But God knows what time it is for each of us. Jesus said that if a sparrow falls from the sky, God knows.

THE LONG ROAD TO GOODBYE

FOR FURTHER THOUGHT...

Illness is usually detected by body talk, i.e., pain, fever, upset stomach, etc., sending us to the doctor for analysis. But Alzheimer's didn't come to us that way. I can see hints of the illness with 20/20 hindsight that I didn't see at the time. Subtle personality changes, incidents of mental disconnect were there, but I didn't see them then.

That's why it is so important to have a diagnosis as early as possible. I told the physician who made the initial diagnosis that I considered him to be one of my very best friends, because he honestly followed his suspicions in determining his diagnosis. Difficult as it may be and harsh as it may appear, it is my opinion that everyone involved is better served by receiving diagnoses as early as possible and therefore give the family more time to begin to adjust to what is coming.

Medical science is making significant strides, and appropriate treatment can at least improve the quality of life. Early diagnosis can start those treatments. And, of course, it gives the Alzheimer's patient and his or her loved ones time to discuss and plan and think through their future.