

IN THE
LINGERING LIGHT

Courage & Hope for the Alzheimer's Caregiver



CYNTHIA FANTASIA

Alzheimer's and other forms of dementia are expected to triple in the next thirty years. While prevention and recovery strategies can help those afflicted at various stages, who cares for the caregivers? This book will help any caregiver navigate their new normal so that everyone involved in the caregiving process feels equipped, nurtured, and up for the task. Highly recommended.

DR. DANIEL G. AMEN, founder of the Amen Clinics for brain health,
author of *Memory Rescue*

I must admit that I was reluctant to read *In the Lingering Light: Courage and Hope for the Alzheimer's Caregiver*. Why read a book I hope I never need? I am very thankful, though, that I overcame my hesitancy and met Cynthia Fantasia—and her husband, Bob—and accompanied her on her journey through this devastating disease. I was immediately drawn into her story and was challenged by her transparency and faith. While her insights and lessons are an indispensable resource for those who must walk this difficult path, her words encourage and equip the rest of us to support and care for those who are caregivers. Thank you, Cynthia, for your gift, not only to the Alzheimer's world but also to the body of Christ.

CYNTHIA HEALD, author of *Becoming a Woman of Excellence* and *The Faithful Way*

There's nothing easy about caring for a loved one with Alzheimer's disease, but Cynthia Fantasia demonstrates that you can do more than just get by. God longs to sustain

you with grace and faith. Readers will find hope and encouragement within these pages.

JIM DALY, president of Focus on the Family

In the Lingerin Light is a helpful read for anyone called to walk a difficult path. Cynthia Fantasia's tender and honest journey with God ministers grace and truth for life's most challenging times.

JEAN FLEMING, author of *Pursue the Intentional Life*

In the Lingerin Light is one of those books everyone should have in their toolbox. At some point, we all will deal with Alzheimer's or one of the many forms of dementia that afflict our human frames. Having a wonderful guide who has walked the journey is a precious gift. Cynthia Fantasia is just such a guide. She's a naturally gifted communicator who speaks from personal experience and gently leads us through the process of saying good-bye to someone we love while they still live.

JAN SILVIOUS, author of *Courage for the Unknown Season*

CYNTHIA FANTASIA

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Don Pape, Publisher

David Zimmerman, Acquisitions Editor

Elizabeth Schroll, Copy Editor

Julie Chen, Designer

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FOREWORD

I AM HONORED to introduce the author of this remarkable book. Cynthia Fantasia is my friend, and soon she will be yours, as you read this very personal disclosure of what happens when a marriage and a family are hit by the terrible blow called Alzheimer's.

Cynthia and I have been friends for more than forty years. Once upon a time, we raised our families in the same neighborhood. Within our church family, we participated in leadership of the women's ministry. I observed Cynthia steadily growing in all areas of leading others because she was so teachable herself.

I enjoyed watching (and applauding) as Cynthia became a speaker at women's events all over the United States. Her

depth, honesty, vulnerability, and humor drew women in large numbers to hear her speak about what it means to be a follower of Jesus Christ.

Then, very suddenly, this wonderful ministry momentum was interrupted with the discovery that her husband, Bob, had been stricken with Alzheimer's. Cynthia had to deal with the question: *Will the things I've been talking about to women work in my own personal experience?*

The answer that followed? Absolutely!

Those of us who were in touch with Cynthia and Bob during those years were astonished at the faith, strength of character, and empathy that arose in Cynthia for her husband as he slowly declined into dementia. The simple truth is this: Cynthia loved her husband well.

In this book, Cynthia is painfully honest and, at the same time, very practical. She makes it possible for readers to learn how to live through the scourge of Alzheimer's with courage, stamina, and faith.

Throughout the book, Cynthia clearly reminds readers that Jesus' *lingering light* is always ready to break through the clouds in our lives. Readers will also pick up on the author's great concern for traps along the Alzheimer's journey, as the spouse becomes more and more the primary caregiver. She speaks openly about the isolation and fatigue that come as the illness reaches its worst stages. Her willingness to unzip her soul is what makes reading this book so helpful. Her insights speak to emotional and spiritual-health issues that arise every day. And—this is so significant—she highlights the importance of supportive friends and family for remaining resilient.

I honor my friend for trying so hard to be thankful for what she had with her husband rather than emphasizing what was being lost as the disease ravaged Bob's mind. This was overcoming with faith, not just surviving.

Bob Fantasia has been gone for two years now. On the first anniversary of his death, Cynthia and her family invited about thirty people to a special luncheon. These people had been especially present to the Fantasias during Bob's illness. The family wanted to express gratitude for the ways they had been loved during those difficult years. As people came together that day, there was laughter, singing, and sharing stories of the grace of God in Bob and Cynthia's lives. It was an unforgettable occasion in which people acknowledged the difference it makes when people know how to love each other and enter each other's most painful seasons.

You are in for an insightful experience. Cynthia Fantasia describes what it is like to walk through so much pain and loss, yet—at the same time—find the lingering light of God's presence. Thank you, Cynthia, my friend, for the great gift of this book.

Gail Mac Donald



CHAPTER 1

BEGINNING THE JOURNEY

*Relying on God has to begin all over again
every day as if nothing yet had been done.*

C. S. LEWIS, *Letters to Malcolm: Chiefly on Prayer*

IT WAS A SUNNY January day, and we were heading to the doctor for Bob's appointment. Just an ordinary appointment—nothing to worry about. Sure, he had been acting a little “off” lately: a bit forgetful, asking the same questions over and over, unable to remember names or dates. But everyone has those problems, don't they? He was a bit depressed—the world had changed, and his skills weren't in demand anymore. He was worried about his favorite aunt because she was old and not doing well. He was just trying to “find” himself.

Or, at least, that's what I told myself.

I was upbeat. I was planning to retire in six months, and we were going to do all the things we just hadn't had time to do: spend more time with our grandchildren, take long beach walks on our beloved Maine coast, perhaps sell our home to begin condo living. I would read those books that had been piling up and have rich conversations with Bob and friends over leisurely cups of coffee. Yes, life held such promise. Nothing would go wrong!

I had lived a happy life. For twenty-four years, I served as pastor of women for Grace Chapel, a large and vibrant church in the heart of historic Lexington, Massachusetts. My career had given me the unexpected opportunity to become a world traveler. If there was an opportunity to go, I did—with Bob's full support and encouragement. And I went without a care, because he was so capable. We tend to accept our happy lives and think they'll always be that way.

Bob had been retired for a few years and was adjusting well. He enjoyed puttering around in the yard and chatting with the neighbors or with anyone who happened to walk by. His career in the environmental field had taken him around the country as he offered consultation in this cutting-edge industry. When not traveling, he taught classes at church to adults who were exploring faith, and his nonjudgmental and lighthearted manner drew many closer to the Lord. He also served for many years as an elder, and his endearing ways made him approachable to all.

But then, there was the forgetfulness.

CHANGES

“I’m going to say three things,” the doctor told Bob. “Red. Sunshine. New York.” They went on chatting for a short time. I repeated those three words over and over in my mind. “Okay, Bob,” the doctor asked, “what were those three words I told you a few minutes ago?”

I was ready with the answer. But when I glanced at Bob, I saw him looking blankly—first at the doctor, and then at me.

After an awkward moment, the doctor moved on to some other cognitive tests. Bob failed each one.

“It appears to be a classic case of Alzheimer’s disease.” I heard the doctor’s words, but they seemed to be echoing from a deep tunnel. Bob seemingly heard nothing, still displaying his warm, engaging smile. *God’s mercy*, I thought.

Alzheimer’s disease is an ugly, tragic disease. At this point, there is no cure. Best estimates are that a new case of Alzheimer’s is diagnosed in America about every seventy seconds. It is not a normal part of aging.

Our son brought it up first. I was not totally surprised, but a bit stunned. It was one of those things when you really only see the signs in retrospect, as if through a rearview mirror. Because my husband was so high functioning, the diagnosis was a gradual unfolding, a very long dusk before impending (though certain) darkness.

—LAURA

Alzheimer’s disease (AD) is a progressive, degenerative disorder that attacks the brain’s nerve cells, or neurons, resulting in loss of memory,

thinking and language skills, and behavioral changes. AD is the most common cause of dementia, or loss of intellectual function, among people aged 65 and older.¹

As the doctor spoke, my heart raced. Yet, at the same time, I felt an unusual calm come over me. I met with the doctor while Bob sat with our daughters in the waiting room. “What can I expect? What’s the progression of the disease? What kind of a time line are we talking about?”

“I just can’t say. I can give you general answers, but each person is so different, there are no definitive answers.” A response that my type A personality didn’t want to hear.

The doctor had a question for me: “How are you going to handle all of this?”

There I sat, a follower of Christ, somehow trying to balance the reality of all the pain Alzheimer’s disease would inflict on us with the hope of God’s care and eternal life in heaven. Without thinking, I responded, “I guess I’m going to live on the other side of eternity.” I would do my best to focus on the eternal, to trust the One who held eternity in His hands, the One who had gone ahead to prepare a place for us and would come back to take us to be with Him (John 14:3).

I had no idea how many times those words would pierce my heart and remind me where my focus had to be. When you are in the pit of caring for someone with Alzheimer’s, it is a daily challenge to look beyond the pain to the hope of eternity.

We walked out of the hospital different people than when we had walked in.

FOG

Bob was fine—just another doctor’s appointment. “I told you I was fine,” he laughed.

But I wasn’t fine. A shroud of gray, a deep fog, seemed to be rolling toward me. Slowly, it marked its path and began enveloping me. Our daughters were quiet. As we walked to the parking garage, cars whizzed by us and an ambulance careened toward the hospital, but we seemed to be walking in an alternate universe. Bob was chattering away and the sun was shining, but sounds were muffled, and all I could see was gray.

That night, after Bob went to bed, I cried out to the Lord. I didn’t ask “Why?” Instead I asked “How?”

Alzheimer’s disease had become an unwelcome guest in our lives, and its presence would grow with each passing day. It felt as if we were jumping in the car and leaving on a road trip without even knowing our destination. How would I navigate this uncertain road before us? How would I make the right decisions for Bob? How could I protect his dignity and provide proper care?

That fog remained, my ever-present companion. I longed to wake up from this nightmare and resume my life as I knew and loved it.

David was having problems crunching grades for his college students. There were other problems also, yet the doctors could not figure out what was wrong. He was seen by a neurologist and diagnosed with frontal lobe dementia. I was stunned. My father had died after a long battle with Alzheimer’s. I knew this was going to be bad.

—LORRAINE

As I sobbed, it seemed as if God heard me and brought Abraham to my mind and heart.

The LORD had said to Abram, “Go from your country, your people and your father’s household to the land I will show you.” . . . So Abram went, as the LORD had told him.

GENESIS 12:1, 4

The Lord clearly told Abraham that He was sending him away from all that was familiar and comfortable. Abraham would leave the land, the people, and the family that he knew and loved. He would go to a place he knew nothing about, to people he didn’t know. And, other than his immediate family, all Abraham would have to rely on was God.

I could certainly relate. Just that afternoon, I had been told that I would embark on a journey that I knew nothing about, would travel a road that was very uncertain, and would most likely have my heart broken on a daily basis.

A GOOD WORD

Many years before, when Bob and I were going through a crisis, a friend had shared, “There is no chaos in heaven about this.” God was not then, nor is He now, sitting in heaven scratching His head, asking, “How did I miss this?” For this new crisis as for that earlier one, there was no chaos in heaven.

He promised me in His Word:

- I shouldn't fear because He is with me (Isaiah 41:10).
- He will never leave me or forsake me (Hebrews 13:5).
- He knew that I was scared—that I was discouraged:
“Be strong and courageous. Do not be afraid; do not be discouraged, for the LORD your God will be with you wherever you go” (Joshua 1:9).

As I thought about these verses, it became clear that I had to choose, on a daily basis, where to place my trust. Would I travel this uncertain road with the One who created the universe, who created me (and Bob), who knows the future because He has already been there? Or would I creep along in the dark, hoping to do the right thing and take the correct turns?

My decision was soon made. There was no choice.

If the shadow of Alzheimer's has turned your world upside down, please remember that the light of God's presence and care will never dim.

The next six months leading to my retirement were exceptionally difficult. I scrambled to find people who would “visit” with Bob for long periods of time so I could work. He had suddenly become confused—not totally, but enough that I didn't dare leave him at home alone.

While we were on a trip to Colorado, I became aware of my husband's confusion and forgetfulness. Upon returning home, we realized he had left his keys at security in Denver. We clung to the hope that his memory issues were due to a vitamin deficiency, but a neurologist confirmed that we were on the Alzheimer's path.

—SARAH

I was blessed with a very understanding supervisor who assured me that I could work from home as needed. But the demands of an active ministry were exhausting. Preparing a Bible-study lecture each week became more draining than energizing. And having my physical body in one place while my mind and heart were in another was bankrupting my soul.

Finally, the big day arrived: I exited the office and my exciting professional life . . . to begin my new career as a full-time caregiver.

And so our journey began, one fog-filled step at a time, with no knowledge of what each day would bring.

Four years passed between the day of diagnosis and Bob's death. There were days and nights—moments when I wanted to just pack it all up. Would I have chosen this path for my life? Of course not. But would I have passed up the lessons that I learned (and am still learning), the love and help from family and friends, and the deep growth in me? Absolutely not!

A doctor friend wrote words that I carried in my heart throughout our journey:

There's a period of time between . . . diagnosis and the moment when a life ends, and that entire period of time contains life. Sometimes this time is months, sometimes it's years, sometimes it's weeks. Far too often we . . . are so distracted by the perceived inevitability of death that the life contained therein passes by, and sometimes we forget to live it.²

In the reality of our sad, uncertain journey ahead, I decided that I would do my best to savor and celebrate the life that Bob and I would have together—in spite of, and in the presence of, Alzheimer’s disease. Don’t let the diagnosis and your circumstances crush you. The shadow will always be there, but there are moments of joy and memories still to be made. Look for ways to savor and celebrate!

DISNEY WORLD

There would be no move to a condo. We were moving to “Disney World”—the Alzheimer’s world of fantasy and forgotten memories in which Bob would find comfort, and where I would need to find some form of peace. In a way, “Disney World” became my slogan, a daily reminder that my life, as I had planned it, had come to an abrupt halt. Bob believed he was fine, so would I spend the time we had together correcting Bob’s “reality” or going along with it?

The choice to go along with it, to “live in Disney World,” proved to be a good one for both of us. I would do the season well (as far as it depended on me), trusting the One who would (and did) always strengthen and lead me.

This is the book I never wanted to write. I had a plethora of book ideas in my head and heart for many years. Somehow, the ideas never found their way to a computer. If you are reading this book as a caregiver to a loved one with the disease, if you know someone who is a caregiver or has been diagnosed, or if you have been touched in

some way by the damage done by Alzheimer's, I am writing to you.

From diagnosis to my husband's death, I walked a lonely and isolated road, far different from the life I had enjoyed. Throughout our journey, though, there were people who chose to walk with us. There was also the continual assurance of God's presence and faithfulness, along with little illuminations or discoveries that would help to make this journey easier. My hope for *Lingering Light* is that it will offer you some light for the next step or two, that you will know you are part of a huge chorus of brothers and sisters who are on this journey, and that my story will give you strength and brighten your day.

As I began to write, I realized that my story is just that, my story. In the sidebars throughout this book, you will read snippets of experiences from what I call traveling companions. Some of these are people I know personally, others are friends of friends. Each was eager to share her story with me.³

"Traveling Light" sections are nuggets of truth that I gathered throughout my journey. I learned that I had to focus on my husband and his needs, but also, I needed to care for myself. Caregivers can't be weighed down by unnecessary burdens or overly busy schedules. You can tuck these nuggets into your heart and ponder them in a spare moment. They are meant to help you focus and prepare for another step in your journey.

I read short devotionals throughout Bob's illness, found lots of quotations (I love quotes) that encouraged me and gave me insight, and loved reading prayers that spoke to the struggle I was experiencing. I share them with you in

the hope that they will encourage you, lighten your burden, and brighten your day, as they did for me.

My journey now is a new one—learning to live as a single person. It is a challenging journey. But I believe with all my heart that nothing in life is wasted, and I pray that you will find hope in these pages, that you will see your loved one with new eyes, and that you will find strength for the days ahead.

Write in this book. Share your heart. Compose your own prayer. God is listening, and His light is lingering.

Traveling Light

A dementia diagnosis starts you on an unexpected and unknown trajectory. But “that entire period of time contains life.” Plan for a demanding trip, but leave time to savor the journey. Trust the One who knows the way.

A Prayer to Guide You

O God, our heavenly Father, whose glory fills the whole creation, and whose presence we find wherever we go: Preserve those who travel; surround them with your loving care; protect them from every danger; and bring them in safety to their journey's end; through Jesus Christ our Lord. Amen.

THE BOOK OF COMMON PRAYER



A NOTE TO CHURCHES

MOST OF MY PROFESSIONAL CAREER was in full-time ministry. For almost twenty-five years, I served as pastor of women at Grace Chapel in Lexington, Massachusetts. Throughout those many years, I have seen how the power of God and the people of God make a difference. People have invited me into their deep hurts and their delightful joys. Exploring the Word of God has illuminated the way for many groping in the dark. And when the Word prompts people to care for others, a beautiful thing happens. But I have also seen the human side of church people who, over time, move away from those dealing with a lengthy illness.

I have always believed that the local church is the hope of the world. Hope is what a hurting world hungers for.

It's what those struggling with and caring for someone with Alzheimer's disease need. Hope is oxygen for the soul. In the pages of this book, I have shared my hurting soul, which was empty at times. I have also shared how many came alongside me (and Bob), offering care and hope. And yet, this type of response is not common in most church families.

“The churches have failed their people,” says ethicist and expert on aging, Stephen Sapp. “Specifically in the area of support for persons with Alzheimer's and their caregivers.”²³

While there is not yet a cure for Alzheimer's disease, and death is always the prognosis, the church can and should lead the way to offer care and support during the Alzheimer's season.

The estimated number of Americans with Alzheimer's disease and other dementias has risen to 5.7 million, from 5.5 million in 2017, according to a report released today by the Alzheimer's Association.

That's an increase of roughly 3.6 percent and largely reflects the aging of the boomer generation.

By 2025, the 2018 Alzheimer's Disease Facts and Figures report projects, 7.1 million Americans aged 65 and older will have Alzheimer's, and by 2050, some 13.8 million.²⁴

These numbers speak for themselves: Alzheimer's is "among us," and every church will be affected. The church is in a unique position to reach out to Alzheimer's families with the love of Christ and a helping hand. The seven suggestions that follow were birthed out of my personal experience of "It would be so wonderful if . . ." Feel free to adapt these ideas to the size, needs, and resources of your church.

1. *Spiritual-Based Support Groups.* I did not attend any support groups while I cared for Bob. I would have loved a group that had a spiritual component, so members could encourage one another to trust in the Lord and His faithfulness. Financially, it would have been challenging to find care for Bob while I was at a support group. Churches could offer a combination: a support group for caregivers and, in another area of the church, a program for the loved ones with Alzheimer's. A few volunteers to help with some easy puzzles, music, and simple art work, along with an approved snack, would give the caregivers a brief respite and their loved ones some socialization.
2. *Sunday School Class.* A class based on simple Bible stories using pictures and music would speak volumes to people struggling with Alzheimer's disease. Memories of Bible stories learned as a child, simple Bible verses, old hymns, and an opportunity to share would pour value into each person. And caregivers would benefit by seeing their loved ones recall the truths of Scripture.
3. *Life Stories.* Bob loved to look through old photographs. Even if he didn't remember names, he would

often share stories (some fictional) about the photos. A great activity for a team of volunteers would be to visit someone with Alzheimer's to document a "life story" through photos and memories. It would be an activity with long-lasting significance as the disease increases and the memories become more distant.

4. *Time, Talent, Treasure.* The entire church family can be involved in pouring value into a person with Alzheimer's. Watch for ways the person can be made to feel valuable. If a table needs to be moved, ask the person to help you move it. If books need to be carried to another room, ask the person for assistance. The smallest of tasks, the simplest of chores can offer a feeling of normality and acceptance to one who feels useless and isolated otherwise.
5. *Memory Café.* Started in the Netherlands in the 1990s, Memory Cafés are gaining popularity in many senior centers. It's a place for those with Alzheimer's and their caregivers to get together for an hour or so, enjoying simple refreshments and conversation with others. A church could offer the same to its families: Volunteers could make coffee and cookies, and family members could drop in for a comfortable time together—not worrying about what people around them are thinking.
6. *Education.* A church could create a brochure providing facts about Alzheimer's and listing ways members can show care and offer help.

7. *A Place to Ask.* Many senior centers have volunteers who are available to answer questions about finances, health insurance, taxes, repairs, and other problems. A church could ask members who are retired professionals to volunteer their time and experience to help caregivers address the myriad of details they must now face alone. Many times, an individual is perfectly capable of sorting through these kinds of challenges . . . until he or she becomes a caregiver. Then, it's all too much! The volunteer can point out when the caregiver needs a professional for particular topics. Just knowing there is a place that offers some guidance is a life-giving gift.

Dr. John Bisagno, retired pastor of First Baptist Church in Houston, Texas, has said, "I have most often seen that, when the people of God are presented with the facts, they do the right thing." As Alzheimer's disease increasingly affects our population, I pray that the people of God will indeed do the right thing. I pray that the "least of these," whose memories are fading and whose families are devastated, will find they do not walk alone through their valley. May they, and their caregivers, be accompanied by burden bearers who share the love of Christ and give the practical help necessary.