

## Introduction

# This Is Not What I Thought Would Happen Next: The Dementia Diagnosis



WHAT WAS the most important day of your life? Perhaps if someone asked you this question, you would answer by talking about the day you were baptized, the magical moment when you became a parent, or the proud time when you earned a promotion at work. But Kristin, sixty-nine, has a different event near the top of her list—the day her husband was diagnosed with dementia. “My life is divided into before and after. On that day, walking out of the doctor’s office, I thought everything had suddenly come to an end,” she says.

Today, Kristin has changed her perspective. I interviewed her five years after she heard this news, and she now speaks less dramatically about her situation. “Overall, my husband and I are coping with this illness [Parkinson’s disease] and with the changes it brought. We even laugh together sometimes, believe it or not. It hasn’t been easy. It’s been the toughest thing we’ve ever gone through, but it isn’t the end of the world either.”

If you are a person who has been diagnosed with dementia yourself, or if you are a caregiver who is accompanying someone with this illness, you may find yourself on a journey that began much like Kristin’s—with a sudden diagnosis and an acute sense of panic. On the other hand, your journey may have started gradually, as you realized more and more each day that there were changes in yourself, or in your partner or parent.

Whether sudden or gradual, the impact of a diagnosis of dementia tends to reorganize a family's entire life. Dementia is a "plot breaker"<sup>1</sup> with the power to disrupt the personal story lines of people who had other plans. "This is not what I thought would happen to me next in my life," Baroness Karen von Blixen tells her doctor in the movie *Out of Africa* after receiving a shocking diagnosis. How true this is for families experiencing dementia.

Kristin and her husband certainly did not expect this development. When they planned for their retirement years, they envisioned travel, volunteer work, and visits to the art museums they enjoy. Kristin told me that adjusting to dementia is an ongoing process. The sadness she feels in letting go of dreams continues, even as she adjusts to a new reality. These days she is always busy.

Sometimes her husband, Tom, can do things for himself, but other times he needs her help with simply putting on a robe. But the hands-on care is not what is most difficult for this couple. Since dementia became part of their lives, Kristin and Tom spend much of their time solving practical problems—getting to doctor's visits, monitoring the side effects of new medications, and working to prevent Tom from falling—again!

On the other hand, Kristin no longer sees dementia as "the end of the world." She has been able to move past her initial feelings of panic to gradual acceptance of their situation. She has learned to problem solve rather than catastrophize, and she is no longer paralyzed by anxiety. Kristin told me that she and Tom continue to have moments of real joy, as when the grandchildren visit, or moments when they can laugh together at "our crazy situation." "The other day we both stopped trying to get Tom's arm in the right sleeve of his sweater, and we laughed. What else can you do!"

Above all, Kristin has been grateful that her Christian faith and her spiritual community have been present in the days since the diagnosis—both the good days and those that are more difficult. "I couldn't have done this alone, without God's help!" she told

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me. As a pastor, and as someone who has been focused on spiritual resiliency in my research and writing for many years, I was naturally pleased to hear her say this. But I was also well aware I must listen deeply to discern the pathways of faith she walked in her everyday life. Why did she feel now that she was going the wiser way?

There is certainly much in Kristin's new caregiving vocation that requires strength, as does her husband's new situation as he lives with memory impairment. They will need resiliency that has spiritual, social, and psychological dimensions. Her task began immediately, right after the diagnosis was given—trying to figure out exactly what all those clinical words meant.

## Understanding the Language of Dementia

One of the first things caregivers like Kristin and their partners have to do when they hear a diagnosis of dementia is become acquainted with a whole world of confusing terminology. Many people, including caregivers themselves, have difficulties with the language used to describe persons with memory or other cognitive problems. What is the relationship between Alzheimer's disease and dementia in general? If someone is forgetful, does that mean they have dementia, or is that simply a normal part of old age?

All people experience cognitive changes as they age, including memory issues and slower response rates while doing tasks such as typing.<sup>2</sup> But when these problems begin to interfere with everyday life, it is time to visit a family physician or a geriatric assessment clinic. Forgotten appointments, losing personal items repeatedly, increased irritability—these are only a few of the symptoms that send out a warning signal. Sometimes, family members find it difficult to take the step of visiting a doctor. Many people who are noticing memory changes find they prefer to deny what's going on rather than face the possibility of a diagnosis they don't want to hear. This can cost precious time, since strategies that can slow down dementia are delayed.

After hearing the word *dementia* from a professional, it is still easy to be unsure of exactly what it means. The easiest way to clear up this confusion is to think of the word *dementia* as an umbrella term under which fall separate illnesses that can all lead to problems with thinking and memory. A diagnosis of Alzheimer's disease, one form of dementia, can be especially difficult to hear since it is closely associated in our culture with the indignities of old age—with helplessness, confusion, and decline—and because it is a diagnosis without a cure. But as Kristin and Tom's story shows, many other illnesses can cause dementia, including Parkinson's disease, vascular disease, and Lewy body dementia. (I have provided a glossary of dementia terminology at the end of this book.) We need to become informed because, as I have found in numerous casual conversations, most people are unsure of these distinctions between the types of dementia and use them carelessly, confusing caregivers and their extended families. Kristin discovered this when she first shared Tom's diagnosis (of dementia related to Parkinson's) with her friends: "I didn't know he had Alzheimer's too!" one woman commented. Clearly, she was confusing the whole umbrella with one of the illnesses it covers.

But getting our medical language accurate is only the beginning of the challenges related to dementia language. One subtle but even more important problem arises when we exclusively use biomedical terminology to describe a human being. In a world of labels and diagnostic manuals, it is far too easy to objectify and dehumanize. If we thoughtlessly use medical terms and rely on labels, Tom, who has a lifetime of experience and a rich, complex personality, becomes, overnight, "the dementia patient with a chemical imbalance." His distress becomes "behavioral symptoms,"<sup>3</sup> and pharmacology seems the only solution. To think solely in terms of medicine is to take away much of what makes a human life valuable. This tendency decreases our motivation to listen carefully. And when we don't listen, we don't respond with sensitivity.

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understand the experience from their point of view. What does it feel like to find that we have forgotten where we live and are unsure of who we are?

## Understanding the Experience of Dementia

A young woman working at a long-term care facility watches a tall, dignified old man walk down the hall. She doesn't fully understand what is going on with him but knows that he has some strange illness called dementia. He is clearly lost. When she asks him if she can help him find his room, he sighs and comments, "I'm a stranger in a strange land."

I was that young woman, more than fifty years ago, and these words were my first glimpse of the confusion that comes with dementia. I was working a summer job as a nurse's aide to help pay for my college tuition, and I was trying to find my own way through the confusing world of an intensive, long-term care facility. The words Mr. H spoke to me that day stayed with me through the years as I went on to a vocation in aging (gerontology)—including five years as a chaplain in a long-term care facility, a call as a pastor ministering to older members of my congregation, over twenty years as a marriage-and-family therapist specializing in aging, and finally as an academic professor/researcher/writer focused on gerontology. I also learned about this illness from being a long-distance caregiver to my own mother, whose last years included vascular dementia. Finally, during the months before writing this book, I learned from eight family and professional caregivers who told me stories about their lives as caregivers.

No one I met, however, has been more vivid than Mr. H in describing his experience—one of the many that I will explore throughout this book, because each person who must live with dementia is different. He was, indeed, feeling like a displaced person—like a stranger in a strange land. In many ways, I remain indebted to him and to his kind effort to share his experience with a naïve young woman who barely understood what he was saying.

I believe that all of us who are caregivers as well as those with impaired memories must learn as we listen to each other and allow the Holy Spirit to awaken our imagination and understanding, albeit in different ways. That principle will inform this book because, as with you who are experiencing life with dementia, I am learning still.

## Who Are the Caregivers?

Like the term *dementia*, the word *caregiver* is used to refer to a variety of people in many different contexts. Some caregivers are family or close friends, living in the same home as the person experiencing dementia. They experience what has been called “the thirty-six-hour day,” after a popular book of that title.<sup>4</sup> Others live close by the person with dementia but not in the same dwelling, perhaps because the person with dementia now needs the intensive care that a long-term care facility provides. Others live out of town or out of state and must help at a distance, often relying on local relatives to give daily care. As I discovered caring for my mother, long-distance caregivers experience a particular set of challenges, including guilt and worry.<sup>5</sup>

Still other caregivers are professionals who visit, counsel, and accompany as part of their full-time vocations. These caregivers are typically compassionate and sensitive people, and some of them have had years of experience with aging persons. They are the nurse’s aides, physicians, nurses, social workers, chaplains, parish pastors, and psychologists. Their task is twofold—to care for a fragile patient but also to care for her partner, family members, and close friends. Many of these professionals become close to family caregivers and share with them important moments in the caregiving journey. Some also provide spontaneous spiritual care: the nurse’s aide who was present when my mother-in-law was dying provided by far the most meaningful prayer that day.

Because we caregivers are such a diverse group, we bring a variety of resources and talents to our work. These resources and talents

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determine, to a large extent, how we respond to various practical needs in our particular care setting. Our responses vary, however, not only from person to person but also across ethnic groups and cultures, and are specific to our historic period. Some caregivers have a wide and loving network of family and friends who are willing to help out, gladly providing emotional support and even hands-on respite care. This network may include neighbors, new friends in an Alzheimer's Association group, or old friends who are members of our congregation. Others feel alone or afraid to ask for help, in some cases because of unresolved family tensions but also perhaps because they were taught, as one woman I interviewed told me, to "be self-reliant at all costs."

Some caregivers have sufficient economic resources to pay for assistance with domestic chores and to purchase whatever equipment is needed, such as elevators and lifts for a family van. Others struggle to meet basic medical bills and must work full-time in addition to carrying out caregiving responsibilities. The depth and range of resources at a caregivers' disposal are important and can't be ignored in any discussion of caregiving.<sup>6</sup>

In addition to varied financial resources, time demands, and health status, we each bring to our caregiving responsibilities a unique combination of strengths and weakness, including our own mix of physical and emotional health. A surprising number of caregivers are coping with chronic medical conditions of their own and are deeply concerned about being able to stay healthy enough to continue as a caregiver. "I just worry about how long I'll be able to keep doing this," mentioned one woman I interviewed who struggles with hypertension.

But we are even more different psychologically. Those caregivers who have battled depression and/or anxiety all of their lives do not leave these challenges behind when they assume this role. Some caregivers use defense mechanisms, such as denial, that have been adequate for other situations in life but do not serve them well now, at a time when it is so important to be proactive. Some of us readily

employ a problem-solving strategy when a crisis arises, while others feel undone by challenges great and small. Some of us are actors in our own private, unspoken story but others have an internal narrative in which they are the helpless victims of circumstance. Some caregivers never lose the capacity for hope, while others find themselves moving gradually toward despair. All of these people are part of the rich, complex mix of human beings who are caring for persons with dementia; all of them are the imperfect yet blessed ones who serve both God and our larger human family.

In addition, all of us have a relational history with the person who now needs our care, some untidy story of love, anger, forgiveness, resentments, bitterness, and empathy. This is the complex way we live together in our partnerships and families. The coming of dementia only highlights the immediate challenges within that ongoing relationship that both bring us together and keep us apart. The interviews I conducted before writing this book were a dramatic reminder of the truth that caregiving always occurs within the unique dynamics of a complex relationship and its intricate past. What an error it would be to visualize caregiving as one man or woman in isolation, giving care at the present moment. We need reminders, in our overly individualistic society, that we are bound together by an emotional and social web that we never fully understand.

Finally, we provide care within the imperfect, ever-changing cultural and historic moment. Life-span psychology has taught gerontologists, including this author, to bear in mind that all aspects of human development occur within a particular society, at a particular time. Our contemporary values impact our caregiving, often without our conscious awareness. For example, the unpaid nature of caregiving tends to devalue this work in our own and others' eyes. On the other hand, our culture provides technical resources that were not available to caregivers in the previous generations, such as social media and other resources on the internet, as well as promising medical research that can slow down dementias such as Alzheimer's disease. These challenges and

advantages will be one of the dominant themes of this book, as I attempt to explore the experience of dementia for care partners as both a countercultural (i.e., Christian) enterprise and as a fortunate recipient of technological advances. These poles become especially important when we ask the question, “What do we hope for?”

### What Might Our Hope Look Like?

During the open-ended, informal interviews I conducted just before writing this book, I always ended the conversations by asking, “What do you hope for?” I chose to leave this question general and did not specify what I meant by hope, in reference to either the person diagnosed with dementia or the caregiver. I was curious about where the person, who was kind enough to struggle with my question, would choose to focus—on her own needs, on those of the person with dementia, or even on our whole human family.

### What do you hope for?

For some caregivers the response was quite specific and revealed an understandable longing for more time and opportunity to meet their basic personal needs. One woman, along with her husband, was caring for her mother-in-law with advanced Alzheimer’s disease in their home. They took turns going out, attending church services, shopping, and so on. She cried a little as she told me, “I just hope to be able to go out to dinner with my husband now and then.”

Another caregiver is presently making plans to move into a cottage that is part of a continuing-care facility. She anticipates getting some respite after the move and admitted she is hoping to take a cruise, perhaps with a close friend. Others focused on the care recipient, as the man who told me, “I just hope I can keep my mother out of a nursing home. Those places are dreadful!” Another hoped to be able to prevent more falls, and a different caregiver hoped for more help from her adult children.

I must confess to having some hope of my own as I conducted these interviews. I hoped that someone would respond by mentioning the hope beyond human hope, namely, the hope offered by our

spiritual faith. Then, finally, in one of the last interviews, I heard just that. Lorna had cared for her mother, who has Alzheimer's, for nine years at home before recently helping her move into assisted living. Articulate and open with me throughout the interview and thoughtful in her responses, she paused for several minutes after I asked this question. Then she spoke, "I hope for dignity and grace."

I was so moved by these words, and all that they evoked, that I chose to borrow them as the title for this book. Although others have spoken of dignity and grace in relationship to aging,<sup>7</sup> it is less likely that we would use these words to describe our hope for a severely impaired person with Alzheimer's disease living in a care facility. But I believe that Lorna spoke for all who are cognitively impaired, and those who give them care, when she so elegantly expressed her hope. To borrow the words of Mr. H, Lorna is acutely aware that her mother is traveling, like a new immigrant, into a strange, new land where everything and everyone is unknown. To navigate that terrain, she will need the two things we all need when we are lost and alone—dignity and grace. She also points to what she, as a caregiver, needs. Her task is often invisible and undervalued, disrespected in our economically driven society. And, like all of us, she needs the forgiving grace of God to move on after experiences of guilt and self-blame.

The words dignity and grace point to many aspects of caregiving. For example, caregivers hope that loved ones will always be treated with respect and seen as more than objects of care. They hope that nurse's aides will respond as promptly as possible to the bathroom needs of the one who is dependent on help. They hope that people will speak to their loved one in a non-patronizing, respectful tone of voice.

I believe dignity is also important for the caregiver herself, even though no one mentioned this. I was unhappy to discover the poor self-care of each person I interviewed, with one exception, Lorna, who said quite directly, "I'm good at asking for what I need." I heard stories of poor sleep, rare hours of respite, inadequate family/

friend care teams, and irregular physical exercise. Overall, the word *stress* echoed in my mind as I listened to the caregivers. While this is no surprise given the demands of their work, it is a real danger as well—for both caregiver and care recipient. How strange that our own needs are often last on our list. I fervently hope that this book will be both a reminder and a resource for improved dignity and self-care for those of you readers who are caregivers.

In addition to everyday, practical challenges for caregivers' health and well-being, there are also practical ramifications to the gift of grace. It takes a certain kind of patience to display repeated tolerance when a person with early stages of dementia repeats a story over and over, or asks the same question repeatedly. It takes grace to respond to the emotional content of words spoken by the cognitively impaired, rather than arguing with their incorrect factual content (we will explore communication techniques in more depth in chapter 2). And it takes grace to first confess our shortcomings as caregivers and then ask for God's forgiveness, thus setting us free to do the best that we can on any given day. It also takes grace for the person diagnosed with dementia to ask for help without irritability or shame—no small matter for those of us who are used to managing our own daily lives.

The following chapters of this book are my attempt to explore what dignity and grace have to do with living with dementia, either as a caregiver or as a person with memory impairment. I will also suggest how such a hope can be present amidst the exhausting, messy, and ambiguous work of giving care when dementia is present. My first "rule" is that there are no rules, at least not for how hope is present in each story. Each one of us has a different way of hearing Lorna's words and of appropriating them into our experience of dementia care. I encourage you to create your own story of dignity and grace as you read, perhaps editing it as you go. Hopefully by the conclusion of this book you will have arrived at a unique perspective of what hope looks like, both in your own life and in the life of the person you love and care for—if not now, then in the near future.

One final word about the book's title—the word “wisdom” in the subtitle refers primarily to the wisdom of the caregivers and persons living with dementia whom I interviewed, worked with as a counselor, and accompanied as a pastor. It also refers to biblical wisdom, particularly the wisdom of the Psalms. Finally, as my editor graciously reminds me, I have developed some level of wisdom myself through years of experience working with both caregivers and those with dementia, and from reflecting on those experiences with my students. Yet as I write this book, I am increasingly aware that we need, above all, the wisdom that God alone can give. “For the foolishness of God is wiser than human wisdom, and the weakness of God is stronger than human strength” (1 Cor 1:25).

### My Theology of Caregiving

Lorna's words echoed for me the heart of Christian faith. First, I feel strongly that we have a dignity that no one can take away because it was given to us by a loving Creator God. Each of us is, first and foremost, a child of God. This core identity came before life handed us a diagnosis or a caregiving role. At baptism we were marked by the cross of Christ, forever. We cannot lose that mark of acceptance and worth even if, through dementia, we lose the ability to remember who and whose we are.

I believe, too, that we are given grace sufficient for all days and circumstances. This astonishing grace enables us to live with meaning and joy, even when we question our own standing with God or feel we have failed to follow, consistently, his will for our lives. We are forgiven; grace is ours—not because we can produce an income, participate in a witty conversation, or follow his commandments perfectly, but rather because the love of God was poured out for us in Christ's work on the cross.

As a Christian, I believe that God entered our world to teach us how to live, but also to replace scorekeeping with abundant forgiveness. I also take particular comfort in the message that, because of the Holy Spirit, we are not alone. I trust—or try to

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trust—in the promise that whatever comes our way, we can dare to hope that grace will abound. We have a story to hold on to that I treasure: God’s word tells us of Jesus—of his gentle healing, of the radical new values he preached, rejecting power and money as the basis for worth.

And I trust that grace will abound because we have a Savior who died in solidarity with our suffering. The great mystery of our faith is that, somehow, all our wounds are now part of Christ’s wounds. When I wonder what has become of the personal suffering and brokenness of those I care for, I have a place to focus—namely, on the broken body of Christ. Paradoxically, it is on the cross of shame that dignity and grace are perfectly visible.

And so, I’m with Lorna. I hope that dignity and grace may be extended to me and to those I love in this life, whatever our cognitive status. I am grateful that these spiritual gifts are promised to us and made certain for all our unknown tomorrows. This includes the day we make our final goodbyes to those we love. Meanwhile, I strive to lean into the dignity and grace that are already mine. For although God provides all that I will ever need, it is up to me—to us all—to claim those gifts and to incorporate them into whatever vocation we choose (or that chooses us). This process of weaving God’s gifts into our vocational lives is, of course, not a onetime event; it requires a lifetime of discipleship. I call the fruit of this labor *spiritual resiliency*.

## Honesty and Hope

As I have researched and lectured and written about spiritual resiliency for many years, I’ve learned that spiritual health is far more complicated and difficult to describe than physical health. Part of the difficulty arises because we sometimes feel constrained to speak of our faith in exclusively positive terms, feeling that we will not be “good Christians” if we admit to doubts, discouragement, and fear. In the eyes of others, and even in our own eyes, we want to be Mother Teresa, while inside we recognize we are more like

David, needing a fresh start and begging God to blot out our transgressions (Psalm 51).

Other complications arise because of the diverse way that spiritual ideas meet our everyday language and thought. For example, in Western culture we are highly prone to speaking of our relationship with God in individualistic terms, even though spiritual resiliency is seldom found in the individual alone. A central theme in this book is the importance of community, both as the place where resources and experiences for persons with dementia and their families can best be found, but also as spiritual community, as the body of Christ.

Perhaps you have a problem with the very word used to name this series of books, *hope*. Caregivers of folks with dementia must learn to live in the moment. If we are too future oriented, hope can be lost. Yet, we cling to God's promises and anticipate a better future, a hope beyond our days of toil and suffering. No cheap and easy sense of hope is satisfactory for those living with dementia, for we must somehow reconcile the event of God breaking into our world to bring us moments of joy, here and now, with the incomplete nature of creation and our longing for the fulfillment of God's reign. We might feel a tension between the present and the future. Christians wish to hear echoes of "consider the lilies of the field" (Matt 6:28) and thus be in the present without high anxiety, but we also believe "you do not grieve as those who have no hope" (1 Thess 4:13), and thus we lean into a future based on God's promises. Accepting the paradox of "already/not yet" is so important to the mature Christian life.

These tensions are at the heart of the Christian experience, including the work of caregiving and the challenge of living with a frightening diagnosis. But if we are committed to speaking the truth, if we can envision our lives as part of a community larger than ourselves, if we can live with the complexity of our position between yesterday, today, and tomorrow, and if we allow the Holy Spirit to guide our imaginations, we will be on our way to the spiritual resiliency we sorely need to meet the enormous challenge of living with dementia.