

PRAISE FOR *MIKE & ME*

“*Mike & Me* is so beautifully written! The author illustrates how she and her husband chose to keep right on enjoying life after his Alzheimer’s diagnosis. Hand in hand they took the leap of faith and embraced the journey together.”

— **Laureen Rogers**, Professional Life Coach

“Rosalys Peel shows couples a path to a full and joyful life, despite one partner’s Alzheimer’s diagnosis. *Mike & Me* is the triumph of courage, grace and dignity over this discouraging disease.”

— **Evelyn Williams**, *Blessings of Dementia*

“Here’s proof that couples who are fighting the ravages of dementia can still have years of quality time together. As a behavioral neurologist who cares for many Alzheimer’s couples, I highly recommend taking not just a page out of this book, but the whole thing!”

— **Glen R. Finney, M.D.**

“To know the road ahead, ask those coming back. Rosalys Peel provides every couple touched by Alzheimer’s with vital information about what lies ahead. Her experiences with Mike show us how to live a full life together, even while facing a devastating illness.”

— **Joni Powers, R.N., B.S.**, Integrative Medicine

“What a timely book! For thousands of couples who are now confronting Alzheimer’s, *Mike & Me* shines welcome rays of hope into fearful and unfamiliar territory.”

— **Doris Fleming**, Chaplain and Co-founder, Creative Expression Outlet

“Pragmatic and heartfelt, insightful and informative, *Mike & Me* reminds us that Alzheimer’s, like life, is about hope, help and abiding love. It is a shared journey.”

— **Bob Le Roy**, Exec. Director, Alzheimer’s Assoc. Washington State Chapter

“Told with clear-eyed and loving honesty, *Mike & Me* describes a journey that no couple ever expects to take, but which comes to so many. Those just starting on the Alzheimer’s journey as well as those well along will be profoundly supported and helped by this powerful and moving account.”

— **Rev. Dennis Tierney**

“A treasured book of suggestions and guidance. *Mike & Me* provides vital new Insights into many aspects of Alzheimer’s, including its impact on family, friends, and especially the patient’s spouse.”

— **Lawrence Murphy, M.D.**, Department of Neurology, Swedish Neurosciences

“The life skills, love and respect that Rosalys and Mike practiced over the course of their marriage are evident as they now decide how they will try to deal with Alzheimer’s at home rather than in a care facility.”

— **Caroline Stevens, R.N., M.S.W.**

“Mike Peel was my patient for more than a decade. This uplifting account makes me cry and smile as I remember how Mike and his adoring wife were able to confront Alzheimer’s so effectively together. As I watch my own 93-year-old mother struggle with dementia, I am inspired to be a better caregiver, daughter and neurologist by Rosalys Peel and her wonderful book.”

— **Lily Jung Henson, M.D.**

“*Mike & Me* is a tribute to how a loving couple and family found an inspiring new way to undertake the difficult Alzheimer’s journey. Maintaining the dignity of the patient, providing a safe place as the disease progresses, pursuing needed resources—these critical issues are part of the wisdom in this lovingly written book.

— **Dr. Dianne Levisohn, M.D.**

“Thank you, Rosalys Peel, for opening your courageous loving heart to share your story and journey with the world. *Mike & Me* is an important book—an indispensable companion offering crucial insights for every couple coping with Alzheimer’s—and doing so on your own terms with courage, grace, and endless love.”

— **Michele Abrams**, Founder, In Concert for Cancer

“*Mike & Me* provides tangible ways to ease the challenges of Alzheimer’s and live each day fully despite a life-limiting illness. It’s an inspiring and profound example of how great joy and beauty can come with (and often through) hardship or suffering. I highly recommend it!”

— **Natalie Rodden, M.D.**, Hospice and Palliative Medicine Physician

“A courageous account that brought tears of joy to my eyes. Each chapter details how love and commitment really can prevail over this deadly disease.”

— **Tom Gorman**, former US Davis Cup Coach

“Knowing we have options and choices when confronting Alzheimer’s is empowering. Rosalys Peel offers a vivid and loving picture of one couple’s decision to live with Alzheimer’s in their own way. This book is sure to help many other couples.”

— **Trudy James**, Chaplain, Producer of *Speaking of Dying* film

“*Mike & Me* is an immediate, practical and essential lifeline for any couple who decides to tackle Alzheimer’s together at home. The author’s insights on the legal and financial concerns that every Alzheimer’s couple faces are worth the price of the book alone.”

— **Jesse Robeson**, Attorney

MIKE & ME



AN INSPIRING GUIDE FOR COUPLES
WHO CHOOSE TO FACE ALZHEIMER'S
TOGETHER AT HOME

ROSALYS PEEL
WITH DAN ZADRA



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**THIS BOOK
IS DEDICATED
TO YOU**

Each year, thousands of American couples are given the disheartening news that a spouse or partner has been diagnosed with Alzheimer's. If you are one of these couples, this book is dedicated to you and your loving family and friends.

It's empowering for Alzheimer's couples to discover that there is more than one way to confront this disease together. In that respect, *Mike & Me* is not just a book, it's a "way."

When Mike was diagnosed with Alzheimer's we made a pact to stay in our own home and to find a way to continue living a full life together. We had no idea how our "stay-at-home" choice would turn out, but we did know we could always turn to one of many excellent Alzheimer's care facilities if it didn't. The lessons we learned are here for you. May they inspire and guide you and your loved one on the journey ahead.

I am grateful to the entire Alzheimer's community—the growing legion of researchers, doctors, nurses, counselors and caregivers who are creating better lives for those fighting this disheartening disease. It's a privilege to share the unique story in these pages, along with fresh information and guidance for Alzheimer's couples everywhere.

In loving memory of Mike Peel
May 23, 1935 to June 6, 2011

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PROLOGUE

~

DEAR READER:

*If you and your loved one are
thinking about dealing with
Alzheimer's together at home, you've
picked up the right book.
Let's get started.*

WHEN MY LOVING HUSBAND MICHAEL, to whom I was married for 45 years, was diagnosed with Alzheimer's, I started keeping a journal.

At first I was just trying to record new information and treatment advice from our doctor. But it turned out that journaling became a very empowering and comforting companion for me over the entire nine-and-a-half years that Mike and I dealt with his Alzheimer's.

My journal was a safe place where I could give words to my worries, concerns and fears. It's where I logged the frustrations and setbacks that Mike and I encountered, but also where I recorded and celebrated our many victories, large and small.

Over time, I became aware that our journey with Alzheimer's was different in certain ways from the experiences other couples were having. You see, Mike and I had decided that, despite Alzheimer's, we would go right on pursuing our hopes and dreams, and we would confront the disease together in our own home, one day at a time. I searched high and low for good information to help guide us on that journey, but I found very little.

That led to the birth of an idea: I decided to journal more instead of less, with the thought that someday I might leave a helpful road map of vital information and guidance for other Alzheimer's couples to follow. What this guidance would look like was an unknown at the time; perhaps it would be a little pamphlet with a few tips, or maybe a short story about our journey.

Later, I had a chance meeting with an experienced and caring writer who gave me this quote by author Toni Morrison: “If there’s a book that you want to read, but it hasn’t been written yet, then you must write it.” The book you now hold in your hands is the result.

TAKE THIS BOOK WITH YOU ON YOUR JOURNEY

Today, whenever I tell people that I lost my husband Mike to Alzheimer’s, I see the concern wash over their faces. Perhaps like you they have heard the usual horror stories associated with this disease, and they just assume that Mike and I must have had a devastating journey together. But I am always quick to tell them that it wasn’t that way for Mike and me.

The truth is, Mike and I went a long way together—as far as the road would take us—and this book will show you how. He died in the end, but he died as we all want to die—with grace and dignity. And not before we experienced years of life and love together.

Mike and I completed our nearly 10-year Alzheimer’s journey together, and now I have returned from the journey to tell you the simple but hopeful lessons that my husband and I learned along the way; and to share how our Alzheimer’s experience was much different from the typical horror stories we have all heard.

Whether you are the one with the illness, or the one who is the partner providing the care, I now know that what Mike and I did and how we did it will help you on your journey too. The decision to manage Alzheimer’s together in your own home, for either all or part of the journey, may not be the right choice for some, but I now know that it should be a viable consideration for all.

Your journey will no doubt be different from ours in certain ways and yet the same in others, for we are now all members of the same brave club. We have all had the same fears and worries: “Can we really do this, and how will we do it?”

I am here to tell you that you can. You’ve picked up the right book, so let’s get started.

Roadless Road

A GUIDE FOR THE ROAD AHEAD

For Mike and me, our challenge (and now yours) was to set out on the Alzheimer's journey together—and to keep hope alive.

EVERY NOW AND THEN EVEN THE HEALTHIEST COUPLES will stop for a moment and ask, “What if?” What if one of us has a stroke? What if one of us has a heart attack? What if one of us is diagnosed with cancer?

Mike and I asked ourselves those same questions through the years but, perhaps like you, we never asked, “What if one of us gets Alzheimer's? What then?”

Each year, thousands of American couples are blindsided by this disheartening disease. I say “couples” because no husband or wife ever makes the Alzheimer's journey on their own; their partner is there too. The moment one partner is diagnosed, the other partner joins the journey. This is not something someone does alone.

When my husband Mike was diagnosed back in 2002, the prevailing opinion in the medical community at that time was that most people with Alzheimer's will sooner or later have to leave their home and go live in a care facility. Mike said to me, “I don't want to leave you and our home.” I said, “I think we can do this at home.” But, could we?

In part, *Mike & Me* is the story of my husband's incredible spirit, courage and sense of humor in the face of a potentially lethal disease. But the main focus in these pages is to chronicle our mutual commitment to do all that we could to prevent this disease

from progressing—and to keep our marriage alive and our home life intact.

If you are a loving partner in an Alzheimer's relationship, I'm sure you already know why Mike and I decided to defy the odds and stay together as long as possible in our own home. This book has been written to share how we did it, and to help you learn how you might do it too.

WHAT TO EXPECT IN THE PAGES AHEAD

I have learned that every couple's Alzheimer's story is different. This disease has a way of taking unexpected twists and turns, not allowing us to know exactly which way it is headed next. Because each couple's path is different, you do not get to know exactly how your journey will go—nor did Mike and I get to know ours. But there are important signs and similarities to look for in all who are ill, and I will share those with you in the pages ahead.

About the only thing Mike and I knew for sure when we first started our journey was that someday there would be a cure for Alzheimer's. We hoped it would be in our time, but our time eventually ran out. Through the years, however, we succeeded beyond all expectations to keep the “we” in our relationship, and we were still “us” to the very end.

For you and your partner, there may still be a cure in the near future, and it may well be in time. No matter how or when that possibility works out, however, you can decide right now that you will take control as a couple and learn how to work through the challenges together as this disease progresses. I want to assure you that the powerful, loving “we” in your relationship can continue through thick and thin, and that it is possible to keep that “we” until the very end.

For Mike and me, our challenge (and now yours) was to keep hope alive as we moved forward with our lives. Never despair. Keep looking for the joys in every day—the subtle joys and gifts that oth-

ers might miss—and keep looking forward to what tomorrow will bring for both of you. In that way the journey can continue with mutual love, meaning and dignity as you walk this difficult path together as partners in life.

“LET’S GET ON WITH IT”

Another thing I now know for certain: when faced with adversity, we humans really are incredibly resilient and resourceful, especially when we stick together. We all have unique gifts and strengths that we can draw on when we are challenged or afraid. Mike and I discovered our gifts along the way, and I promise that you will discover yours too.

Mike’s gifts were many, partially because he had already experienced significant difficulties in his life. He had always survived and prevailed in the past, so he naturally decided he could do this with Alzheimer’s too. He made up his mind in the beginning how he would manage the illness, and this approach worked for him and for me.

After the initial diagnosis, Mike experienced a period of disbelief and anger, but he then said, “Let’s get on with it,” and we did. Together, we made the most of each day until the very end, and that made all the difference.

The gifts I brought to our Alzheimer’s journey were different and unexpected. Part of my background is in nursing, but that didn’t really play a big part because I hadn’t provided patient care for many years. Surprisingly, it was my experience as a parent educator and couples’ relationship facilitator that eventually provided Mike and me with some of the missing tools we needed to deal effectively with Alzheimer’s.

During the early stages of Mike’s illness, I was helping to create the couples’ relationship workshops at Swedish Medical Center in Seattle. These workshops are based on research by Dr. John Gottman, the best-selling author of *Seven Principles for Making Marriage*

Work. They are designed to help couples strengthen their relationship and develop an effective way to handle conflict, especially in times of stress or hardship.

It turned out that some of these same insights helped Mike and me preserve our long-standing relationship despite the stresses and hardships of Alzheimer's. I look forward to sharing these and similar insights with you and your partner in the pages ahead.

PART I



Discovering Mike
Has Alzheimer's

WHAT'S WRONG WITH MIKE?

A continuing pattern of foggy thinking and forgetfulness eventually led to a startling diagnosis.

EACH YEAR APPROXIMATELY 450,000 PEOPLE are formally diagnosed with Alzheimer's in the U.S. alone, and the numbers are on the rise. More than ever before the discouraging images of Alzheimer's patients in decline are now featured in the media, leaving all of us saddened and on edge. If we forget where we left our keys, or can't remember someone's name, or don't recall why we walked into a room, we begin to worry, "What's wrong with me? Do I have Alzheimer's?"

For the majority of people, of course, those worries are empty balloons. But, for Mike and me, a continuing pattern of foggy thinking and forgetfulness on Mike's part eventually led to more serious concerns and, finally, to a startling diagnosis.

I want to share the timeline leading up to that diagnosis in this chapter so I can give you a useful snapshot of how our subsequent journey with Alzheimer's progressed. Again, while our journey will differ from yours in certain ways, my hope is that one aspect will be the same: Mike and I decided to travel the road together, with love and dignity from start to finish, and that mutual decision ultimately made all the difference in the quality of our remaining years.

HOW WE DISCOVERED MIKE HAD ALZHEIMER'S

Believe it or not, the initial concerns surfaced nearly four years before we received the formal diagnosis of Alzheimer's. I began to no-

tice that Mike was having more than simple memory issues. I might have to say something three times before he “got it.” Our friends and family chalked it up to plain old forgetfulness. More and more, however, Mike was not responding to what I said, and not following through with things he did hear. This was becoming a chronic problem for us. To make matters worse, he didn’t understand what I was upset about, and I didn’t understand why he didn’t follow through on the things we talked about. (At this point, you are probably thinking that you, too, have Alzheimer’s. But hold on—not so fast.)

For a while Mike tried to solve his “forgetfulness” problem by simply jotting things down in a little notebook to jog his memory. When that didn’t work, we both finally acknowledged that we needed help figuring this out. We made an appointment with our nurse practitioner and told her about the difficulties we were having. She thought the culprit might be hearing loss or sleep apnea and scheduled the appropriate tests.

Mike’s hearing tests took weeks to finalize, but it was finally confirmed that his hearing was fine. I was told that I just needed to talk to Mike up close, and he just needed to be more focused. Hmm.

From there, we turned to sleep apnea as the potential problem. Mike spent a night at the sleep study clinic and—sure enough—he did have sleep apnea. We were set up with a CPAP (sleep apnea machine) which he had to use at night. It was frustrating for Mike, but at least we were now hopeful that we had found the cause of his mental lapses. He simply had sleep apnea, and life would soon get back to normal with the magic CPAP machine. But it didn’t.

For Christmas that year we surprised our young adult children, Kathleen and Patrick, with the gift of a January trip to Hawaii. Mike and I would go along to share the adventure of our kids’ first trip to the islands. How could we not enjoy a trip to Hawaii in the middle of a gray northwest winter? It was going to be wonderful!

With enthusiasm, we practiced packing the CPAP machine (with mask, cords and plugs) into a backpack, and thought all the trip

preparations were covered. Then, out of the blue, Mike announced that he didn't think he could go. He had a contract with a company that had given him some deadlines for work to be done and reports written. It seemed that Mike was having a problem completing the work to their satisfaction and had some reports sent back for him to properly redo.

Eventually, he decided that he could make the trip to Hawaii, but would have to bring his work along. Okay, I guessed that would have to be the way it would work. He assured me that his work would not interfere with our trip and, because I wanted him to come, I believed him.

A reality check came our first day in Hawaii. While the children and I went to the beach, Mike stayed in our family-friendly condo to work on his reports. Later, when I offered to proof his work, I saw immediately that his reports were disorganized and difficult to read. The next day, when our son Patrick offered to stay at the condo to help, he, too, discovered that Mike was having major problems with basic writing.

Patrick, who had been away for four months, told me privately that he now felt his dad was worse than the last time he had seen him. That was helpful information because I was apparently too close to the situation to recognize how things were deteriorating. Every day, now, I worried, "What's wrong with Mike?"

OUR CONCERNS INCREASE

After our Hawaii vacation we went back to our nurse practitioner for advice. This time we were referred to a neurologist. After multiple appointments, an MRI and other lab tests, the doctor gave us the results of Mike's neurological workup. Good news! The results were all negative; Mike apparently did not have a neurological problem. The neurologist said he didn't really know what was wrong with Mike, but it was not Alzheimer's. He prescribed conventional antidepressants. Antidepressants? We were both relieved to hear Mike

did not have Alzheimer's, but was it really depression?

After that doctor's appointment, we walked down the hill to the ferry in silence. When we stopped at a crosswalk, Mike turned to me and said, "Do you think I'm depressed?" I said no, and Mike never did take those antidepressants.

We returned to our nurse practitioner once again. This is probably sounding familiar to you because virtually every Alzheimer's couple I know or hear about has had a similar frustrating and meandering experience on the road to the final diagnosis.

In our case, our nurse practitioner convinced us to get a second opinion from a different neurologist, Dr. Lily Jung. After four years of wondering, "What's wrong with Mike?", it was Dr. Jung who finally sat down with us and said, "I'm pretty sure this is Alzheimer's." The emotional impact of her conclusion was both devastating and confusing. (More on that in the next chapter.)

It was confusing because we now had two different medical opinions—depression and Alzheimer's. And because we did not want to believe it was Alzheimer's, we went to the University of Washington Medical Center for yet another opinion. After a new string of tests, the doctors at the University told us that, while they still couldn't be absolutely sure, they, too, thought it was Alzheimer's.

Still no one-hundred-percent conclusive diagnostic test, but our hopes were now dwindling. At that point we returned to Dr. Jung, who would remain Mike's trusted doctor for years to come, providing the skill and loving care that is needed with this complicated illness. Dr. Jung decided to prescribe an Alzheimer's drug called Aricept. She said that if Mike responded positively to Aricept, it would be another key indicator that he did, in fact, have the disease.

In March, we had a follow-up visit with Dr. Jung, and she confirmed that the Aricept seemed to be working. Our daughter Kathleen reported that, with Aricept, her dad could now order lunch and knew what he wanted and how he wanted it. And I reported that Mike could now focus on what I was saying and that I didn't

need to repeat my sentences three times.

Because Mike couldn't perform those tasks and others competently without Aricept, the results were conclusive. We now had to face our fears. What was wrong with Mike was Alzheimer's.

INSIGHTS

- While searching for the final diagnosis, I learned many things along the way, including: Alzheimer's is just one of many forms of dementia, so it can be difficult to diagnosis.
- Because there are many forms of dementia, the doctor is on the hunt to pinpoint the real problem. Once the problem is officially diagnosed as Alzheimer's, only then is it possible to effectively start treating the illness.
- Your loved one's increasing inability to recall things is typically a key symptom or "clue" that he/she may be developing Alzheimer's. It turns out that the collective experiences of all family members can combine to provide a clearer picture of whether or not recall seems to be deteriorating. In our case, for example, our son Patrick (who had not seen his dad for a while) was able to help us assess that his dad's memory was definitely getting worse.
- A hearing problem is frequently one of the first complaints of Alzheimer's couples. So if you really feel there is a hearing problem, but the first hearing test is negative, then seek a second opinion. Don't be content with, "You just need to focus or listen better."
- As new research dollars pour in, things are changing for Alzheimer's patients. For example, we may soon be able to diagnosis the disease much sooner. Be sure you have a neurologist who stays current on the latest discoveries and improvements. Get on the Alzheimer's Alert list, and stay current yourself with what's in the news. For the most part, good news is on the way.
- Early diagnosis is becoming more frequent and accurate today. And, once diagnosed, people are being treated with more effective lifestyle choices and changes to slow progression of the disease.
- By all means you should feel comfortable getting a second or third opinion. Alzheimer's can be difficult to diagnose. Getting that second opinion can give you the same certainty—one way or another—that Mike and I needed to move forward with our lives.
- Finally, keep hope alive. As I write this, there are teams of researchers

who are closing in on new treatments to slow or perhaps even stop the disease—and many believe they are almost there. So remain optimistic and forward looking. By all means, continue to pursue your dreams, stay healthy and active, enjoy each day and look forward to each tomorrow.

- Remember always that you are not alone on your journey. More and more our entire nation is coming together to find solutions to this disease and help those who are fighting.

CHAPTER 2

THE DAY WE GOT THE DIAGNOSIS

Alzheimer's! The word itself is big and haunting. Hearing the formal diagnosis that day triggered an immediate mix of raw emotions, new fears and uncertainties.

THE DAY YOU OR YOUR PARTNER HEAR that you have Alzheimer's is like no day you have experienced before or will experience again. Shock and disbelief arrive first and then your hearing seems to short circuit, making it impossible to comprehend what the doctor says next.

Looking back, I remember Dr. Jung coming into the room and sitting down with Mike, Kathleen and me that day. Quietly but firmly she explained that, after reviewing the latest neurological tests, she thought Mike did in fact have Alzheimer's. She said a few other things after that, but I have no idea what they might have been. My mind was racing. I thought, "How can it possibly be Alzheimer's? Just a year ago we were assured it was *not* Alzheimer's!"

I remember Mike, Kathleen and I all fell into silence together. After sitting with us for a short time Dr. Jung said, "I'll be right back" and stepped out of the room. She was gone for quite a while and I now realize she was giving us time and space to absorb what we had just been told.

While the doctor was gone, we began to assure each other that this was not possible—that it must be a mistake. Maybe it was depression like the previous doctor had said. (At that point a diagno-

sis of depression was sounding like a blessing because we could fix depression—and we all knew there was no fix for Alzheimer’s.)

By the time Dr. Jung returned we had formulated our thoughts and questions, especially, “How do you know it’s Alzheimer’s?” Dr. Jung replied that the way Mike had been responding to the assessment tests ruled out depression. Plus, the way we (his family) had been reporting the steady decline of his memory was consistent with Alzheimer’s.

It’s difficult to remember all the emotions that ran through my mind that day. What Mike and I felt and said is a blur, but I remember it helped to have our daughter there. We did not cry that day; those tears would come later. We left in disbelief and slight defiance, vowing we would get a second opinion to see if the diagnosis was correct.

It turned out that seeking that second opinion at the University of Washington Medical Center a few weeks later helped get our feet on the ground and prepared us for the new journey ahead. By then, we had slowly settled into the stark reality that the Alzheimer’s diagnosis was accurate. When the Medical Center assured us that this was the case, we finally accepted the verdict as bravely as possible—and then began to gather our strength to deal with this new reality.

INSIGHTS

- Some people fear diagnosis so much that they actually put off going to the doctor. They would rather not know if something is wrong.
- Try to see diagnosis as an alarm that has gone off in your home. Yes, the alarm is telling you that something dangerous has entered your world, and that’s pretty scary. But at least now you have been alerted and can deal with it.
- Every journey begins with the first step. By seeking and securing a clear diagnosis, you and your loved one have already taken that all-important step.

HOW LONG DO WE HAVE?

Once Mike and I had accepted the diagnosis as real, two big questions arose.

MIKE WAS DIAGNOSED BY DR. JUNG IN JANUARY, 2002 at Seattle's Swedish Neurological Institute. This was nearly four years after we first noticed something was wrong with Mike's cognition.

After we calmed to the diagnosis, the first obvious question was, "How long do we have?" We were told at that time that people with Alzheimer's typically live about nine years after diagnosis, and that the last two years are usually spent in a 24-hour care facility. Learning that we probably still had a number of good years ahead of us was somewhat reassuring. It was neither a long time, nor a short time. But Mike and I both felt it was time enough to continue pursuing some of our dreams, to make plans for a meaningful future, and to hold out hope for new medical advancements or even a cure along the way.

Today the Alzheimer's Association gives a fairly large range in how long someone might live with Alzheimer's. No two people are identical, so trust your doctor to give you some useful statistical estimates for your personal circumstances. You'll find that having an estimated time frame can help you gauge the best life choices, going forward.

But here's a word of caution: Don't buy in to strict time limits, for they tend to become a self-fulfilling prophecy. The truth is, neither you nor your physician knows exactly how much time you and your loved one have been allotted on this earth. Who knows how

well you might adapt to the disease and exceed expectations? Who can tell where medical research will be in a year, two years, or five years from now? So, pay attention to the latest guidelines and statistics, but do not consider them cast in stone.

WHEN WILL IT GET DIFFICULT?

The second question that arose right after diagnosis was, “When will life start getting difficult with this disease?” Life for us was not difficult when Mike first got the diagnosis. True, he often forgot things, or misplaced things, or couldn’t recall what I told him, but we were still able to enjoy a somewhat normal life like most couples. So the pressing question for both of us now became, “How long will our life continue to remain somewhat normal—and when might it become more difficult?”

Most in the field of Alzheimer’s describe the last two years as the most difficult and I would agree. But I would also say that the last eight to ten months of Mike’s illness were the hardest.

And yet—and this is such an important realization—Mike and I were never more in love, or more tuned into each other than the last year of his illness. As you will see in upcoming chapters, those final months hold tender memories for me, and I know they were tender times for Mike too.

For now, just know that you, too, can make the Alzheimer’s journey more positive than negative, and that even in the late stage, it is possible to share the journey together and make it meaningful right to the very end.

Again, I want to emphasize that Mike and I had nine-and-a-half years together after diagnosis. The first seven years were easier than the last two. But I want you to know that we created many wonderful memories during each and every one of those nine-and-a-half years—memories that our children, grandchildren and I continue to treasure.

Looking back, I now know that the pact we made to stay together as long as possible in our own home was the critical element in determining the quality of our Alzheimer's journey. The details of that pact are described for you in the next chapter.

INSIGHTS

- Being diagnosed with Alzheimer's is not an imminent death sentence. Statistically speaking, much life lies ahead for you and your loved one after diagnosis.
- I like the saying, "We are living with—not dying from—Alzheimer's."
- Beware of time limits. No one, not even your doctor, can know with certainty how much time you have. As of this writing, there is still no cure for Alzheimer's, but times and treatments are changing and improving even as I write this.
- Have faith, and move forward with your life, knowing that every remaining year can be very meaningful and worthwhile. And remain hopeful that even if a near-term cure is not probable, it is possible.

PART II



Preparing Together
for the Road Ahead

MIKE AND I MAKE A DEAL

*Not long after the diagnosis,
Mike shared his deepest concern
and greatest fear with me.*

AFTER WE RECEIVED THE OFFICIAL DIAGNOSIS and had our immediate questions answered, Mike and I both retreated for a while into a kind of stunned silence.

With the diagnosis, your life has been turned upside down. All your hopes and dreams have been altered, for now you know there is no easy solution to this “little problem” that you had hoped would just go away with the right diet, more exercise, a few crossword puzzles, or a pill.

As time progressed, the diagnosis brought with it a lot of new emotions. We were both doing our best to process this new reality. Down deep, we each had our own separate fears which we were mulling over but not yet ready to verbalize to each other.

Instead of confronting or discussing our biggest fears, we busied ourselves with the obvious practical concerns: reviewing our finances, evaluating our insurance, seeing an attorney, and arranging for Mike to give me Power of Attorney (more on that later). None of these were pleasant tasks. Understandably, Mike resisted addressing them at first, but we eventually agreed to meet them head-on—sooner rather than later—so he could share in the decision-making.

At first, I thought things were going as well as possible under the circumstances. But Mike was obviously angry over the diagnosis and began to be uncharacteristically short with me and grouchy

over even the smallest things. I have been told that anger is actually a symptom or expression of other underlying emotions, such as sadness, grief, and disappointment. I think all were present for Mike, but the one I saw most at this point was anger. Yes, I understood why his usual pleasant personality had now become so difficult, but it wasn't easy being at the other end of his frustration. I wondered, was this how it would be throughout the course of his illness? I hoped not.

I THINK WE CAN DO THIS AT HOME

One day while we were working in the yard, Mike was grouchy once again. I wondered what was on his mind. I walked closer to him and he said, quietly but clearly, "I don't want to leave you and our home."

I don't want to leave you and our home! There it was, a simple statement of his greatest fear. It wasn't death or the loss of his physical abilities. Mike's deepest fear and greatest concern was the prospect of eventually having to leave our home and me—to go live in a care facility.

I understood immediately and moved closer. Without much hesitation I said, "I think we can do this at home."

We talked a little more, it was emotional; I don't know exactly what was said in the yard that day. I do know that, by the end of the conversation, Mike's tone of voice and attitude had changed. We had made a deal with each other—a mutual commitment: As long as it was safe for him and for me, Mike and I would live together in our home and make the Alzheimer's journey together. If, for some reason, our stay-at-home plan didn't work, we could always turn to an excellent care facility as our plan B. But for now, we had made a pact to stay together in our home.

"Let's get on with it," he said finally. I wasn't quite certain what that meant to Mike, but I was pretty sure it meant, "Let's not waste any more time on being sad or grumpy; let's get on with enjoying life to the fullest as long as possible."

That was my desire, too. We had made a deal, and I was determined to do my part and more. But somewhere in the back of my mind I heard that persistent voice, asking, “Did I just make a deal that I cannot keep?”

INSIGHTS

- After months of brooding and sadness after the diagnosis, Mike finally got to, “Let’s get on with it.” That new attitude was so important.
- Moving forward, Mike often said, “There isn’t any point in being upset or angry, there isn’t anything I can do about it.”
- Mike’s change in attitude was huge in how we prepared for the Alzheimer’s journey ahead and made all the difference in how we continued our next years together. We had both concluded that time had not run out on our dreams and aspirations yet. Instead, our mantra became, “Let’s savor every moment.”
- In my “couples’ relationship” classes I teach parents the importance of being a team and working together to solve problems. Mike and I had done a pretty good job with that over our 35 years together. The question now was, could we continue to do it with a disease like Alzheimer’s?
- My greatest fear in this early stage was that we would no longer be a couple at the end of our time together. I now know that, despite Alzheimer’s, it is possible to keep your love, friendship and relationship intact right up to the very last day.