

My Journey with Sumi

*A firsthand account of caring for my wife
who was diagnosed with Alzheimer's disease at age 59*

by Kanu "KC" Mehta



Praise for My Journey with Sumi

Over the past 28 years, I have known KC Mehta as a cheerful, helpful and enlightened business colleague, and I have recollections of Sumi as a gracious host who shared in his cheer.

KC is Sumi's flag bearer of love and affection. My Journey with Sumi reflects the loneliness – and the determination – inherent in providing care to give Sumi a normal life. Doing the right thing may be the more difficult option, but it is always the better option.

What drives us to extraordinary acts? Perhaps a fire within ourselves, a passion we don't necessarily understand. KC has that passion and drive to give Sumi's life joy and meaning. I admire his dedication, sacrifices and unselfishness and feel great pride in having him as a friend.

I hope My Journey with Sumi has a positive impact on caregivers everywhere by raising awareness of Alzheimer's, explaining unique and successful approaches to care, and fostering empathy for all who are forever changed by this disease.

Ratan Tata

Chairman Emeritus, Tata Sons and Tata Group

In My Journey with Sumi, KC courageously guides us through his deeply personal and emotional odyssey that follows his wife's Alzheimer's diagnosis. His transformation, achieved through the powerful tenets of love, mercy and compassion is both inspiring and humbling.

As Sumi's condition evolves, so does KC's response, embodying the principles of Kaizen. His unique, hands-on approach of creative problem-solving and one-on-one, person-centered care has ensured Sumi's safety and well-being for over a decade.

My Journey with Sumi is not just a narration of endurance; it is a beacon of hope, shedding light on Alzheimer's and its care. It stands as a testament to increase awareness and to combat the stigma and taboos often associated with this disease across cultures.

Anand Mahindra

Chairman, Mahindra Group

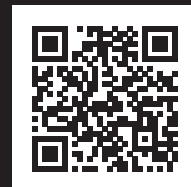
My Journey with Sumi is an extraordinary account of a husband's caregiving journey after his wife is diagnosed with early Alzheimer's disease. I was enthralled by his story, his insights and his love. KC tells his story in a way that makes it unique yet universal.

Filled with his and Sumi's experiences, from early life to the present, Sumi's Alzheimer's challenges him to find new ways to love and care for her. He provides ingenious and practical tips useful for both family and professional caregivers.

His engineering background brings a fresh approach to the continuous problem-solving that dementia caregiving requires. This is a book I recommend to lay and professional audiences – a true gift from a gifted writer and caregiver!

Peter Lichtenberg, PhD

Director, Institute of Gerontology
Wayne State University, Michigan



<https://myjourneywithsumi.com/>

Praise for My Journey with Sumi

What a privilege it is to experience the love story of Sumi and KC. Throughout the journey over the years, one can only admire and celebrate the devotion KC has shown Sumi while navigating the waters of Alzheimer's disease. Reading his words describing his innermost thoughts, challenges, coping mechanisms and self-doubt, we can only catch a glimpse of the all-encompassing role of being a care partner.

The progressive nature of the disease has mirrored KC's continuous attention to provide a safe and emotional connection to his dear wife along with recognizing the need to be cognizant of his own self being. It is an honor to provide a small form of respite through our program "Art of Caregiving®", by using art as an outlet for expression. The intimacy we have experienced with KC and other participating care partners is the reward in itself for investment into this program. Knowing that we are helping to make a few hours in a week a place for reflection and creativity is gratifying.

I am humbled to have a slight moment in this passage of KC's time. Thank you for sharing your thoughts and challenges through your beautiful words.

Annie VanGelderren, President & CEO, Birmingham Bloomfield Art Center

The only other person I know who frequently uses the Japanese term Kaizen, meaning continuous improvement, is my former boss who is a self-made billionaire. Clearly, KC has a billion-dollar brain to go with his one in a billion heart!

Abby Pungot, a family friend

KC's book struck a special chord with me as two very dear people in my life passed away with dementia. My mother with Alzheimer's long ago, and recently, my brother-in-law with FTD (Frontotemporal Disease). My wife, Sudha, and I took care of my mother at home for many years. KC's book rekindled those memories as he humbly and truthfully shares the trials and tribulations of his Journey of love, dedication, sacrifice and total devotion. A husband who is so gifted with the talents, management skills, innovative mind and in-depth analytical skills. The book is riveting till the end and the examples and the side stories put forward by KC keeps it moving smoothly.

KC is a unique partner, a Kaizen practitioner, and if not a Saint than definitely a close to one. We all are grateful to him for sharing his journey and teaching us the meaning of "love is the answer." The book will be great addition to the library of each and every caring person.

Dr. Harish Rawal, MD; FACS, Neurosurgery (Retired)

I met KC Mehta when he spoke to a group of male caregivers during a workshop sponsored by the Detroit Area Agency on Aging. In a matter of moments, as he began to share his decade-long caregiver journey, I knew the voice of an experienced male caregiver is the optimal way to reach other men caring for the women in their lives. The entire audience was spellbound.

And now, with *My Journey with Sumi*, KC offers a book that offers heartfelt testimony to the unselfish attention required of all caregivers, particularly those caring for spouses living with dementia, like his wife of 50 years, Sumi.

Beginning with the diagnosis of Sumi's early onset Alzheimer's disease, KC created a new normal for her. He focused on the person-centered care she deserved, always attentive to her comfort and safety. As she changed, he adapted. And the book includes numerous care strategies that helped KC adapt. Above all, KC offers a universal message of love and empathy that bridges all cultures and human connections.

Ronald S. Taylor, President & CEO, Detroit Area Agency on Aging

Your book is so informative and full of common sense. For example, the list of Instrumental Activities of Daily Living (IADLs) in your book and website will be so helpful when I need to prepare such a guide for a future caregiver for my husband. Your book will be as valuable as a reference as most of the books on caregiving that I have tried to force myself to read. Thank you, my friend.

Denise, a caregiver friend

KC, my friend, your unselfishness dedication is an inspiration to all of us. Saying you have done too much would be an understatement. Once again you don't stop at just doing "The Thing." You thoroughly research, analyze the pros and cons, bring clarity and then implement. Also, in yet another step beyond: You educate us.

When someone is down, I refer them to the *My Journey with Sumi* website for inspiration. I also share your blog messages to many and explain this is not just about Alzheimer's. It's about an approach to living through difficulties. It's about focusing, creating a process, converting challenges into opportunities, problem solving, and flourishing through THINKING. I, too, read the online Bible you have created about caregiving to center myself as required. Bravo and God bless you. Stay happy and healthy.

Jignasu Sheth, a friend

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A MESSAGE TO THE READER

This book contains the author’s ideas, views, suggestions, references and recollections of experiences that helped him, and his wife, navigate their Journey. It is intended to provide helpful and informative material on the subject addressed in the book for people who have Alzheimer’s disease, other forms of dementia and memory loss. The reader should understand that the author is not providing professional medical, health, legal, financial or other kinds of professional services in the book. The reader should consult his or her own medical, health, legal, financial or other subject matter expert before adopting any of the ideas, views, suggestions or author’s experiences offered in this book or drawing references from it.

As the reader, please note that what may have worked or be applicable in the author’s situation may not work or be applicable in your case. Appropriate approaches to dementia care will be the result of your own and your loved one’s efforts and particular situation, and countless other circumstances beyond the author’s knowledge, experience and control.

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To order the eBook or for any other inquiries, please visit the website:
<https://myjourneywithsumi.com/>

Our Journey is dedicated to Sumi, my wife of 50 years, whose effervescent smile, easy demeanor and serene silence has inspired me. It is not me who has written this book. Sumi has placed the pen in my hand and given an unlimited supply of ink. I am just the instrument.

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Preface

In 2013, at the age of 59, my wife was diagnosed with younger onset Alzheimer's disease. Sumi and I had been happily married for over 40 years but other than brief times of normal sickness I had little experience in caregiving.

As a former engineering executive at Chrysler, my problem-solving analytical mind hoped for a misdiagnosis. But as I researched the disease by reading every book I could find, I came to accept Sumi's situation. I, eventually, turned to soul searching and reflection to get us both through the first three years of our Journey. At first I wanted to change Sumi, but I learned that instead I needed to change myself to best meet Sumi's needs.

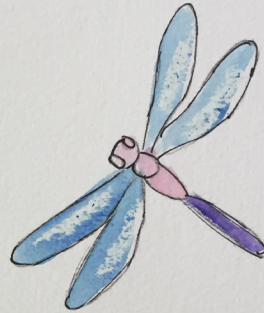
I first wrote formally about Sumi's disease in 2015. With the encouragement of my family and friends, I continue to write a journal called My Journey with Sumi on WhatsApp. It allows me to channel my emotions, document the changes we go through, and share glimpses of our lives

with others.

I write "in the moment" without dwelling on them. I find it therapeutic.

I refined some of these rough writings into chronologically ordered essays. This documents the emotional turbulence I went through during the initial phases of Sumi's disease and how I came to emotional acceptance and management through research and reflection. In some essays I flash back to life prior to Sumi's disease. But all my essays can be read in any order and individually. Some ideas and concepts are repeated to give reference to the theme of that essay.

In the following pages, I would like to share these essays to increase awareness of Alzheimer's disease, reduce the stigma associated with it, and help others in similar situations find solace. These essays are also on my website, *My Journey with Sumi*, and can be accessed by using this link: <https://myjourneywithsumi.com/>.



KC
6/21/18

Part 1 – My First Letter to Family and Friends about Sumi’s Alzheimer’s Disease

August 9, 2015

Dear family members and friends,

Diwali and Christmas are usually the best times to reflect on all that’s happened during the year...good and not so good. Well, this is not that time of year as Michigan’s summer is pleasant and idyllic. But with some time on my hands, I thought this was the best time to share what has transpired in our lives lately.

The most significant event in our life is Sumi’s health.

When well-wishers, friends, and family ask how Sumi is doing, a short and simple answer comes, “She is fine and doing well.” As her condition does not require any active treatment from doctors there aren’t any status or progress reports to give. Hence, the simple but difficult answer.

Sumi suffers from dementia of the Alzheimer’s type. Normally, this disease strikes people in their advanced age but it’s not uncommon to manifest in younger years, 50’s and 60’s. No one knows the exact cause of Alzheimer’s disease. It strikes people from all walks of life. Some prominent people who had this disease are President Ronald Reagan, Prime Minister Margret Thatcher, Secretary of State Cyrus Vance, and Washington Post Executive Editor Ben Bradley. Others still are boxer Floyd Patterson and actors Jimmy Stewart, Charles Bronson, and Charlton Heston.

Generally, the disease begins near the hippocampus—the brain’s memory center—and then spreads to the areas of the brain that control language, judgment, and motor control. In the earliest stages, before symptoms can be detected with current tests, protein pieces called beta-

amyloid (BAY-tuh AM-uh-loyd) clump together to form plaque. Since beta-amyloid is chemically 'sticky,' the gradual build-up of plaque kills neurons and then forms 'tangles' of protein fibers that disrupt the neurons' transit system. Eventually, communication between neurons breaks down, affecting learning, memory, thinking, planning, speaking, understanding speech, and the sense of where your body is in relation to objects around you.

This is a degenerative disease, meaning the plaques and tangles get worse over time. There is no cure and no treatment to stop the spread in the brain. The rate of progression varies greatly. The course of the disease depends in part on the age at diagnosis and whether other health conditions are involved. In later stages, individuals lose their ability to communicate, recognize loved ones, and care for themselves.

The following link has more information in the form of a slide presentation with a healthy brain versus a brain with the disease: www.alz.org/braintour/.

When one door starts to close, others open up...that's what is happening to me. As a caregiver, I am learning new behaviors, attitudes, interpersonal skills, habits, and the running of day-to-day chores.

Sumi is mostly cheerful. However, when

I am tense or upset, she becomes tense and upset. Conversely, when I am relaxed and happy, she is relaxed and smiles. She directly reflects my mood. I do upset her sometimes, but I continuously strive to be aware of my behavior and actions to try and be more loving and compassionate. This change in my mindset has benefited me as well. I believe it has reduced my anxiety and stress and also improved my well-being, both physically and mentally.

Sumi and I cook together. She mostly preps and cleans, and I do the rest. We have been eating very well and lately she has, intentionally, gained a few pounds. She takes care of her daily routine, albeit slowly. I have learned to shop for her clothes and how to help her wear her sari when we go to parties. Many challenges married couples face are from the difference of opinions and how one goes about discussing and resolving those differences. When I reflect on my life as a young male raised in a competitive Indian society and its education system, it's typical to develop traits of an 'alpha male.' I strove to always be right...always correct. I hated to lose arguments, marital or otherwise. Now, though, taking care of Sumi I have to consciously control my 'alpha male' tendencies and remind myself that she is right, even when she isn't, due to her medical condition. It feels good to purposely lose a point. And I wish I had developed this awareness of letting go earlier in my life.

Life's ambiguity teaches new lessons. Having trained as an engineer, one becomes self-critical and manifests excellence in everything one does. When you create or rig-up something, you try to achieve the best quality in fit, finish, and craftsmanship. Now I still control what I can but have learned not to control the uncontrollable. When I notice Sumi hasn't cut the vegetables evenly or is drying the slightly soapy dishes before completely rinsing them, it does not matter. The food tastes just as delicious and the dishes are still clean and hygienic. Equanimity is now the name of the game.

There are hardly any dull moments. The tasks vary widely. In a day, I can be tending flowers or tending Sumi's needs. Power-washing the driveway or washing clothes. Fixing something in our newly renovated kitchen or fixing a meal. Working on my consulting assignments or consulting with doctors. Reading at least five to six online newspapers. Calling India to connect with family. Grocery shopping (the best cilantro deal is at the newly opened Patel Brothers with two bunches for \$1). Paying bills. Going for my daily three-mile walk... and so much more. Sumi has been great through it all. Always ready to participate, help, or patiently observe.

Some 20 years ago, it was common to take Dale Carnegie's 12-week long, once-a-week, course or read his book *How to Win Friends and Influence People*. One of Dale

Carnegie's principles is the 3 C's: don't Criticize, Condemn, or Complain. I had taken this course but find practicing the 3 C's difficult. Sumi never took the course but I have observed her practice the 3 C's throughout her life and even now. She has influenced me more than Dale Carnegie ever could.

As I write this, it is a beautiful, perfect summer day. Bright setting sun, low humidity, and 78° F. These summer days will soon change to autumn and then cold brutal winter, but today is a day to enjoy. I am like a mountaineer, who plans assiduously to scale mountains. His moment-to-moment tasks boil down to prepare him for the next step he is going to take. Every next step is his first step. He does not dwell on the extraneous.

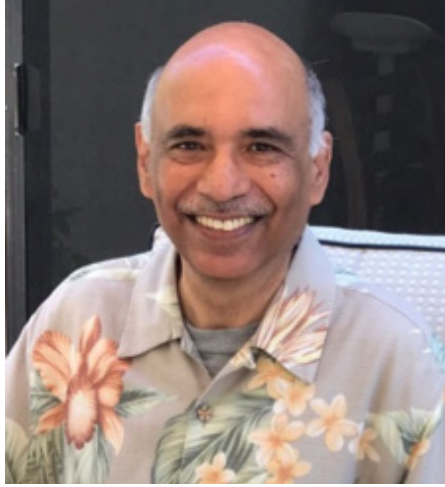
A Hindi song from the movie *Waqt*, sung by Asha Bhosle with music by Ravi and lyrics by Sahir Ludhianvi, comes to mind:

*Aage bhi janey na tu
Piche bhi janey na tu
Jo bhi hai, bus yahi ek pal hai*

Translation:

*You don't know what lies ahead
You can't change the past
All you have is this moment*

Sincerely,
Kanu C. (KC) Mehta



Kanu C. (KC) Mehta

President, KC Mehta Consulting, LLC

Mr. Mehta retired from Chrysler Corporation in 2007. He held various positions in Engineering, Management and International Business Development. His work included various strategic positions in the area of international business development and partnerships, corporate strategy, material cost reduction, and in the development of new products and processes where he honed his problem-solving skills.

Mr. Mehta began his more than 40-year career in the Michigan based automotive industry, starting with eight years at Ford Motor Company and 23 years with Chrysler. After his retirement, Mr. Mehta was Senior Consultant to Tata Technologies for six years where he was instrumental in the development of Passenger Electric Mobility Concept vehicles called eMO2. He later consulted with the Michigan Economic Development Corporation (MEDC) in support of MEDC-led investment missions to India to increase inward Foreign Direct Investment.

Mr. Mehta holds a Master of Science degree in Mechanical Design from the University of California at Berkeley and a bachelor's degree in Mechanical Engineering from Walchand College, Sangli, India.

Since 2015, Mr. Mehta has been a full-time care partner for his wife who has Alzheimer's disease. Mr. Mehta writes blogs and speaks at various forums to increase awareness of Alzheimer's disease. This book chronicles his experience as a care partner for his wife.