

My Journey with Sumi



January 22, 2020

Rochester Hills, Michigan

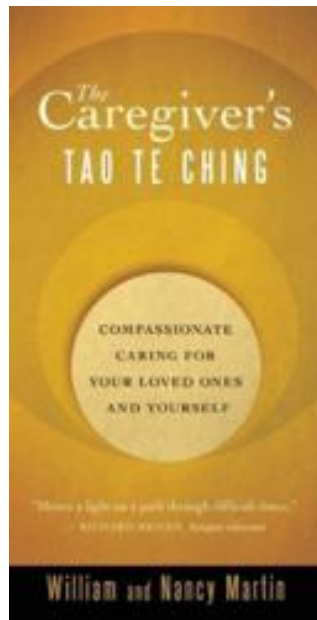
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My Journey with Sumi Part: 17

Healing Ourselves

Tuesday, October 8, 2019—5:30 pm—68°F (20°C)—Beautiful, a sunny and unusually warm fall day



Over the last two and a half years I have written about the changes that have taken place in me as a care partner to Sumi. With these changes have also come the acceptance and wisdom that life does not unfold according to our own wishes.

Recently, I came across a small book, *The Caregiver's Tao Te Ching* by William and Nancy Martin. This book expresses encouragement and wisdom from the classic Chinese text, *The Tao Te Ching* written by Lao Tzu, a legendary figure from some 2,600 years ago.

The Caregiver's Tao Te Ching has 81 single page chapters. Each chapter begins with a poem followed by a brief commentary.

I like Chapter 33, titled *Healing Ourselves*. It gives a voice to my own experience and journey as a care partner over the last six and a half years.

Below, I'd like to share this chapter:

"Healing Ourselves

Understanding what another person feels

Is helpful knowledge.

Knowing what we ourselves are feeling

Is essential wisdom.

Easing another's pain

requires certain kind of skill.

Easing our own pain requires true power.

Healing ourselves

is the greatest act of caregiving.

Much of our suffering stems from believing that we know what other people think and feel. We act on these assumptions, only to feel hurt and rejected when our words and actions are not welcome.

In our Tao mind, we take nothing personally and remain with our own experience. We cannot know what our care receivers are experiencing. Their attention moves from one physical sensation to another and from one internal story to the next. Their response is not about us, but a reflection of the inner work they are doing. Stepping back, we look at our own heart. What are we experiencing? What are the fears and the anxieties, the hopes and expectations that we carry right now? Can we focus compassion on our own heart where the turmoil exits?

Considering these questions, we reenter our direct experience. We do not need to understand what others are going through. Accepting our own inner dynamics, we find new balance and calm. We can wait, open and available, so we will be ready when they can share what they need."

My Journey with Sumi: 18

That Which Is Within

Sunday, October 13, 2019—12:30 pm—55°F (13°C)—Beautiful, a sunny and cool autumn day

Throughout our lives, Sumi, my daughter Parini, my son Jasen, and I have traveled to many nations. Individually, I have traveled to more places for international assignments for Ford and Chrysler and even a few as a consultant.

Even three years after Sumi's diagnosis, we traveled internationally. I traveled more often, though, due to consulting assignments. There were times when I used to make three or four international trips every year. Over more than four decades I have traveled to 29 countries, some more extensively than others.

I have been to six countries in the Americas: USA, Canada, Mexico, Costa Rica, Venezuela, and the Bahamas.

And fifteen countries in Europe and North Africa: Germany, UK, France, Italy, Vatican City, Switzerland, Austria, Denmark, Sweden, Finland, Estonia, Russia, Turkey, Egypt, and Tunisia.

In Asia I've visited eight countries: India, Nepal, Thailand, China, Taiwan, Hong Kong, Japan, and South Korea.

All my traveling has come to a full stop now. In the last four years I have traveled only two times. Each for a short five days, away from home and Sumi.

When a kite flies in the sky it appears to the kite that it has a lot of freedom. But really, the kite is tethered with a string and is managed by its handler. The kite only has limited freedom. True freedom only comes when the kite is cut from its string and flies away carefree in the drifting wind without a predetermined destination.

On many occasions I miss the good-old-days and wish to travel carefree. But that is not so. As they say, when one door closes another opens up. As a care partner to Sumi, a few new vistas have opened to me.

From the book, *The Caregiver's Tao Te Ching* by William and Nancy Martin, chapter 47 exemplifies my feelings.

Below, I'd like to share this chapter:

"That Which Is Within

*We may feel cooped up by our care giving,
doomed to watch the world go by
outside our window.*

*Yet, we are given a window
that opens on the heart –
a vista few people ever see.*

*We don't travel to faraway places,
yet knowledge, understanding and wisdom
come to us right where we are.
It is not what is outside that satisfies,
but that which is within.*

There is no way to describe the vividness of life that unfolds between the caregiver and care receiver. There is no clearer view of our heart and mind. All our beliefs, hopes, and fears—even those we felt we had put to rest long ago—emerge with new intensity. We feel tension, fear and uncertainty one moment and a breaking through into peace and confidence the next. We find that compassion is not a soft, delicate thing but that which brings clarity and courage.

We see total vulnerability in the one we are caring for. The tenderness, wisdom, and courage of her heart become visible as she struggles to control the flow of life and health. Here in this room, we discover more about ourselves and each other than many decades have revealed before. What a sweet, amazing vista we are given as caregivers."

My Journey with Sumi Part: 19

My Story, *My Sumi*, Essay Contest Organized by Area Agency on Aging 1-B

Thursday, October 17, 2019—4:15 pm—52°F (11°C)—A nice and sunny autumn day

A local entity, The Area Agency on Aging 1-B, helps individuals and their family caregivers maintain their health and independence by providing home and community based long-term care services. They have organized a caregiver's story contest and have invited caregivers to submit their stories.

I submitted my story today. It was limited to 700 words and mine came in at 697. There will be one winner from each of the six local counties. The winners will be announced on November 1st and they will be recognized and awarded \$500 during the caregiver appreciation award luncheon at the Troy Marriott on Saturday, November 16th.

Below is my story, *My Sumi*, which recaps many things I have written here before.

My Sumi

In 2013, at the age of 59, my wife Sumi was diagnosed with Alzheimer's disease.

In the natural aging process, we change physically, biologically, emotionally, and mentally. All the changes that come from the natural aging process were thrust upon our family at an unnatural and rapid rate when Sumi was first diagnosed. I was not prepared. I went through phases of shock, denial, guilt, and grief. Followed by a lot of research and reading on Alzheimer's disease. This enabled me to enter the phases of soul-searching, self-analysis, reflection, and acceptance. Acceptance brought changes in me.

For me, being an effective care partner, has two aspects: creative problem solving and emotional acceptance. For the former, drawing from my career as a problem-solving engineer, I have invented, designed, and rigged up solutions for Sumi's safety and well-being. This aspect of caregiving gives me small victories as I test solutions to make Sumi's life more comfortable.

For emotional acceptance, it is recognizing that Sumi is not a problem to be solved, but a person to be loved and cared for deeply with compassion, patience and mindfulness. As Sumi is

changing, it becomes incumbent upon me to change my perspective as well. I began to differentiate that when Sumi is extremely difficult, it is not her, but the disease. When she is smiling, it is her true self and not the disease.

Sumi is in the late stage of Alzheimer's disease and needs full-time assistance with feeding, toileting, showering, and dressing. She cannot verbally communicate her needs and discomforts. Despite that, she eats and sleeps well. She is physically fit and walks about 4 miles daily.

To be an effective care partner, I realized the importance of maintaining my well-being. I hired a part-time caregiver to assist Sumi freeing me to educate myself, reach out for help and to make time for myself.

To educate myself, I took "Powerful Tools for Caregivers" classes offered by the Area Agency on Aging 1-B. In these classes, I learned many strategies and tactics to become an effective caregiver. I also attended a seminar by Teepa Snow, one of the world's leading educators on dementia, for a deeper understanding of Alzheimer's.

For self-care, I attend "The Art of the Caregiving" classes offered by the Birmingham Bloomfield Art Center. We learn many different forms of art as an outlet for expressing ourselves. During the class, I get so engrossed in the art projects that momentarily I forget about caregiving. I also attend CALM, caregiver's self-care and wellness program, offered by THRIVE at the WSU.

As another form of self-care, I have started writing about my experiences with Sumi through an on-line platform titled My Journey with Sumi. I write candidly about our lives, my thoughts, and feelings to increase Alzheimer's awareness. My writing relieves me from brooding, and I find it therapeutic.

Part of reaching out for help is receiving and giving support. I attend two support groups which provide an outlet to openly share my feelings and learn from others. I share my experience with others who are beginning their journey. Fellow caregivers tell me they find comfort and inspiration from my experiences/writings.

The hardest part of the caregiving is that it is a lonely journey in spite of getting tremendous support from family and friends. It can feel that all dreams and hopes are on pause. Sometimes, I feel as though I am on a cliff's edge. But with steadfastness, I amaze myself that I have scaled a new height in caregiving. What I thought was a cliff is just another plateau - a new normal.

Changes in Sumi have precipitated changes in me and opened up new internal vistas. Sumi gives purpose, clarity, and focus to my life. I strive to become a better person and husband by being more loving, caring, compassionate, and patient by maintaining emotional equanimity and mindfulness. I am able to recognize the important things and let go of the trivial. I try to control the controllable and manage the uncontrollable. My anxiety, stress, and the blood pressure have been reduced thereby improving my well-being. I find that I am compassionate, self-healed, little wiser, and at peace with myself.

UPDATE: I am excited to say my story is one of the six winning contest entries! I am not a writer and have never written until becoming a care partner to Sumi. This is very humbling and gratifying. My writing is now getting a voice so others can benefit from it.

My Journey with Sumi Part: 20

Celebration of Life – Humility

Sunday, January 19, 2020—6:15 pm—21°F (-6°C)—Partly Cloudy

Within one week, loved ones of two people from our Alzheimer's support group passed away. One's mother in her 70's on January 12. While we were still digesting this sad news, Mike's wife Suzy passed away in the early morning of January 16. She was 62 and she had been diagnosed about 8 years ago.

During our Alzheimer's support meeting in the evening of January 16, Mike stopped by and spoke for few minutes. Mike was well composed and described the last few days of Suzy's life. Suzy had stopped eating and drinking. She would just drink few drops of water. Hospice nurse had given morphine (not that Suzy was in pain, but I learned that in such situations, it is a protocol to give morphine). On January 15, Mike went to sleep around 11:30 pm and woke up 3 hours later to check on Suzy. Suzy at that time was taking her final breaths and as soon as she saw Mike, she stopped breathing as if she was waiting for Mike to come to say goodbye.

Next day, On January 17, I shared the following email with the support group.

Dear all:

Yesterday was one of the most difficult day for our group and for me. First, we learned passing away of one person's mother and while we were still digesting this sad news, we were hit by Suzy's passing away. I never met both but felt so close to them from how their loved ones used to tell stories about them and describe their daily trials and tribulations.

Kudos to Mike for taking time to come to the meeting and being so composed in telling about what transpired in the last days of Suzy's life.

All these have been swirling and weighing on my mind.

Sumi is 65 and in the 7th year of her disease. I know what happens in the late, late stage and what could happen to Sumi. I don't want my mind to go there but I can't help. The power of visualization is a positive force that allows to achieve great things, but it also can create negative thoughts / forces. On days when sometimes Sumi does not eat well or refuses to drink, my mind races forward thinking: Is this the beginning of a new phase?

With Linda and Suzy as backdrops, my mind visualizes the scenarios of Sumi's end of life. Would I be able to continue to keep her at home? Would she be in the Nursing Home? In the Hospice? My children who are in Los Angeles - how will they be involved? There are no answers to all these, and I know that I should stay in the present and take one day at a time. But this is the struggle - anticipatory grief vs. living in the present - we all face during our journey.

All I can do is love Sumi even more!

Warmly.

KC

Today, on January 19, I paid my last respects to Suzy at the AJ Desmond Funeral Home in Troy, Michigan. She looked calm and in eternal peace.

Whenever I have gone to the Desmond funeral home, visitors are normally seated in the rows of chair facing the casket in the cove in the front. Immediate family members stand near the casket and visitors form a line to pay their last respects. After that family and friends give speeches and tributes to the person passed away.

Today, at the funeral home, the atmosphere was not somber. The ambience felt like Celebration of Suzy's Life. The visitation was from 1:00 pm to 7:00 pm. People were coming and going during this period. Visitors were standing wall-to-wall and mingling and talking in a small group of 3 to 5 throughout the room. If it was not a funeral home, one would think they just walked into a (no-drinks) graduation party.

Mike was his usual - well composed, equanimous and talking one-on-one with the visitors. He told me that he is not sure how he will be the next week when everyone leaves. There were lot of photos of Suzy with family and friends. Photos were spread across the room on the tables and easels. As people came in the room, they walked toward her casket by themselves and paid their last respects, one-on-one.

One way to see today's event and the atmosphere in the room is that our loved ones with Alzheimer's are dying a slow death every day, like dying from the thousand cuts. Carepartners grieve throughout the journey. So, when the final moments come, carepartner's grieving tank must be almost empty with a sense of relief that the on-going sufferings on everyone's part has ceased and make a resolve to transcend these emotions into the Celebration of Life.

After coming home, I read a poem #39 from the book The Caregiver's TAO TE CHING and found solace in it.

Here is the poem with its narration:

Humility

Despite our seeming maturity,

we know that we are little children,

Utterly dependent on the Tao

and helpless without it.

So we care for others with humility.

We do not act as if we are virtuous

or possessors of a special power

but as if we know how fragile

and precious life is.

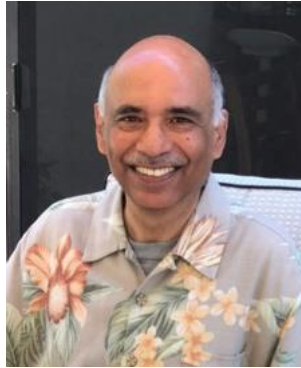
How can we help but be kind?

EVERY YEAR WE WATCH the cycle of living, dyeing, stillness, and rebirth in the turning of the seasons. The leaves of the fall trees blaze in the glorious colors. They gradually fade and fall. When the gray of winter ebbs, the ends of the branches will show the tiny green fringe of new leaves budding. It is soothing to know that our lives are unfolding in the same ageless rhythm. Life is fragile and transient, and this makes it rich and vibrant.

Understanding this can add layers of wonders to our caregiving. Those in our care know that this hold on life and health is tentative. They become our guide, taking time to really taste a bite of cinnamon roll. They patiently watch the play of wind in the branches of a tree.

This fall, we know we may never share another change in the seasons. There is one leaf left on the maple tree outside, and rain is starting to fall. We grow still, sitting next to each other. Today we will just watch in case we get to see that last leaf float gently on the ground.

My Brief Bio



Kanu C. (KC) Mehta – President, KC Mehta Consulting, LLC

Mr. Mehta utilizes his extensive automotive industry experience in corporate strategy, business partnerships, material cost management, and product processes and development, as well as his skills as a strategic thinker. Mehta has a keen ability to create new initiatives in technical and international assignments.

His 40-year storied career in Automotive includes 23 years with Chrysler, 8 with Ford and 6 years of consulting with Tata Technologies and 3 years of consulting with Michigan Economic Development Corporation. After working on several advanced vehicles at Ford's Body and Chassis Engineering group in Dearborn, Mr. Mehta joined Chrysler in Highland Park, initially in Body Engineering. He then held a senior position in advance product development at Chrysler's Liberty Project, where he honed his skills in advance product creation, material, and other cost savings.

In 1993, he moved to Chrysler's International Operations as an executive, where he developed new corporate relationships with companies in Asia Pacific, especially India, to assess the market feasibility of Chrysler's products for sale. Mr. Mehta developed a wide network of Auto Industry contacts in India by closely working with Mahindra & Mahindra, Tata Motors, Bajaj Auto, Hinduja group, Maruti, Hero Motors, Confederation of Indian Industry (CII), Automotive Component Manufacturers Association of India (ACMA) and Society of Indian Automobile Manufacturers (SIAM).

By 1998, Mr. Mehta returned to Chrysler's Advance Vehicle Engineering, in Auburn Hills, serving as key liaison for his company's advanced vehicle engineering work with Design Office and the Platform Engineering. In 2004, he assessed the potential for profitable long-term participation in the Indian auto industry for DaimlerChrysler. Later, assignments for the German-U.S. automaker included a significant electric vehicle business study, a material cost management study resulting in a \$6 billion gross cost reduction over 5-years and development of a Chrysler's recovery and transformation plan.

Mr. Mehta was Senior Consultant to Tata Technologies for 8 years - from 2007 to 2015 where he was instrumental in the development of Passenger Electric Mobility Concept vehicles called eMO1 and eMO2

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.