

My Journey with Sumi

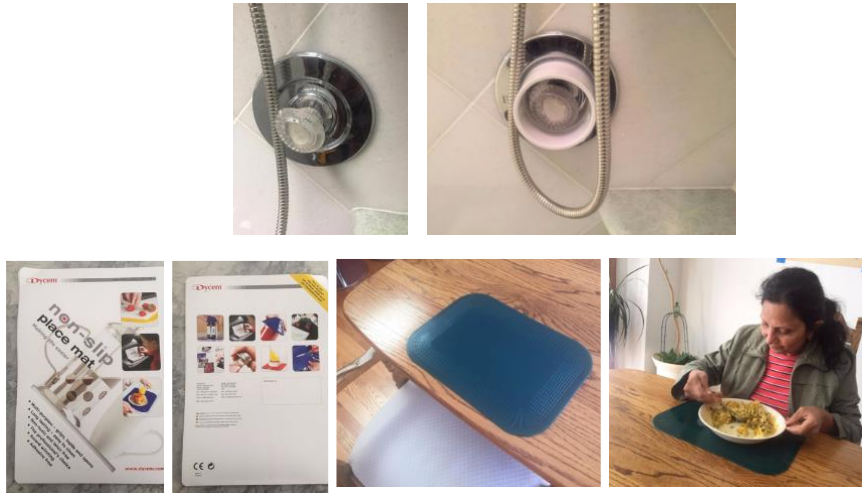


January 22, 2020
Rochester Hills, Michigan

My Journey with Sumi: Part 6

KAIZEN—Continuous Improvement

Sunday, March 18, 2018—12:50 pm—48°F (9°C)—A bright, sunny day



Last week was uneventful as Sumi's behavior and mood has been steady and predictable. She is very playful.

In the Japanese language, there is the word KAIZEN (改善) which generally refers to the continuous improvement of all functions and processes. With time on hand, I have been practicing KAIZEN in Sumi's care partnering by looking for ways to improve our daily tasks.

One problem I had been facing was while giving Sumi a shower she would accidentally reach out and turn the knob that controls the water temperature—or sometimes she would wiggle the water hose which would then move the knob. This splashes us with cold or scalding hot water. I looked into buying a temperature control knob which is often seen in European homes and hotels. These controls are expensive, require a plumber to install, and could easily cost \$1,000 in parts and labor. After brainstorming with a friend, I came up with a simple solution that would only cost \$1.48. I bought a 4" PVC plumbing coupling, cut it to the right length, and glued it to the back plate of the shower knob to protect the knob from being accidentally turned. Now, that problem is solved.

But another problem also needed my attention. While Sumi was eating she would fidget and move her plate, making it hard to eat. Sometimes, frustrated, she would even throw the plate and food from the table onto the floor. While searching for a solution I found a placemat made by a British company called Dycem. The placemat not only sticks to the table but sticks to whatever you put on it, keeping it still. Now, Sumi's plate doesn't move. She is less frustrated and can eat from her plate. I highly recommend this placemat for anyone with small children or people with special needs.

I also noticed while eating at night, the interior of the kitchen is reflected on our sliding glass doors. Seeing her own image, my image, and other reflections in the 'mirror' Sumi would get distracted. So, I installed a pull-down blind and the problem was solved.

Also, lately, Sumi doesn't want to drink smoothies from a leak-proof tumbler with a straw. To help, I started giving her smoothies in a bowl mixed with her medications, ground almonds, and ground walnuts to make it thicker. She's been eating this with a spoon and, for now, it seems to work.

Sumi, also, has not wanted to drink water from a glass. So instead of water, I have been giving her a big bowl of watermelon pieces. Since watermelon is 92% water and 6% sugar, approximately 450 grams of watermelon equals about 2 cups of water. I hope this keeps her somewhat hydrated and perked up with sugar. Luckily, Sumi is not diabetic and her fasting sugar level is in a good range so there is no other side effect from eating watermelon.

KAIZEN (改善) has become a watchword for me. As Sumi changes, every challenging situation provides a new opportunity to become an effective care partner by drawing from my career as a problem-solving engineer to practice KAIZEN (改善).

My Journey with Sumi: Part 7

The Saddest Day of Our Lives

Monday, April 23, 2018—1:30 pm—63°F (17°C)—Beautiful, warm with blue skies

As it happens, April 24, 2018 will be five years since we first saw the Neurologist about Sumi's problems. For the last 15 months I have been writing 'in the moment' in *My Journey with Sumi* regarding the happenings in our lives and about my feelings and emotions.

So far, I have not written about the initial stages of what precipitated us to see a neurologist. But for the last few days I have been reading the reports the doctor wrote after our first visit, five years ago. I am going to mention a few things from his reports here, as the doctor has very well captured the events leading up to our visit, including the testing for Alzheimer's disease and his diagnoses.

Reliving this history is very difficult and emotional. It brings me tears but I hope it increases the awareness of this terrible disease to the readers of *MJWS*.

A little over five years ago, on April 9, 2013, a family friend had arranged an all-ladies luncheon party at her house. Before Sumi left I felt apprehensive about Sumi driving herself. I'd begun to notice driving lapses, like missing an exit when picking me up from the airport or how Sumi would show up late if we drove separately to meet somewhere. Other times, when she would drive with me as a passenger, I noticed her reflexes were slow. It took her longer to make decisions about making turns and the drivers behind her would honk their horns.

Around 1 pm, I got a call from Sumi. She was lost about one mile from our friend's house. I tried to give her directions over the phone but she wasn't able to follow them properly and after getting frustrated stopped answering my calls. Sumi had difficulty hearing in her left ear and the surgery to correct it required her to wear hearing aids but due to the difficulty in using them, she had not been wearing them. Also, she had gotten a brand-new phone the day before and I thought she must have been confused on how to use it.

Our friends and others went out to help look for Sumi. When I still didn't hear from her, I got concerned and called the police. Then I informed our son and daughter, who live in LA. There was nothing I could do except hope the police would locate her.

Around 5 pm, Sumi was able to make it home on her own. When she arrived she was distraught and I didn't have the guts to probe her on where she had been or how she made it home. Even to this day it is a mystery.

When fellow caregivers describe the one event that made them seriously seek professional medical help for their loved ones, invariably, it is about the loved one getting lost. In one case, a husband was missing for 24 hours and was found about 150 miles away from his home. In another incidence, a woman was driving the wrong way on a one-way street into oncoming traffic. Yet another instance, a woman wanted to go to the store but ended up about 90 miles from home. Navigation problems, that is getting lost while driving or walking, is one of the early tell-tale signs of dementia. Typically, other tell-tale signs of dementia exist at least 1-3 years or more prior to people seeking medical help. Now, in retrospect, people realize early detection and getting in to see the doctor is very important. Medical science is changing fast and early treatment is helpful, both medically and emotionally.

In Sumi's case, getting lost on that day for an extended period of time was the trigger-point that made me seek professional medical help. Two days later, on April 11th, we went to see Sumi's primary care physician who asked us to see a neurologist. A close friend gave us a referral and per the neurologist's advice, on April 22nd we got an MRI, with and without the contrasting dye. In the morning on April 24th, just before our appointment with the neurologist, we had an EEG test done. An EEG, or electroencephalogram, is a test used to find problems related to electrical activities of the brain.

Below, I'd like to share some of the report from Sumi's neurologist based on my input during our April 24, 2013 meeting. Just a reminder, this was five years ago.

Mrs. Mehta is a 59-year-old right-handed woman of Indian origin who was brought in by her husband. The reason for the consultation was memory difficulty and episodes of confusion. Mrs. Mehta's problem began approximately a year and half ago and has been insidious and progressive over that time. The primary information provider is Mrs. Mehta herself and does not

have any clear complaints. She appears to be in the clinic at the request of her husband. She has been having a little bit of flat affect, although she denies being depressed. She is sleeping well. However, at times, she appears to be confused. On some occasions her husband notices that when she is talking to her kids over the phone she would be making a good conversation, but at other times she would not be very much engaged and appears to be confused. She has also, at times, forgotten names and further details of some of the family members. About three months ago, she once ended up leaving the household stove on. On one occasion, she went to her friend's place, which was about 20 miles from their home and required a complicated drive, and she got lost. Finally, she was able to make it home on her own, but was unable to provide much detail. At that time, she also had a new cell phone and had trouble figuring out how to use it. Last January she went to visit her children in Los Angeles and while returning home, her daughter dropped her at the LA airport but she missed her flight. Ultimately, she was able to negotiate with agents and was able to rebook the flight on another plane to reach home the same day. Again, the details of the incident remain sketchy according to her husband. She also notices to have some difficulty with calculations and simple arithmetic. She has been able to maintain her routine without difficulty.

Mrs. Mehta herself denies any complaints. In specific, she denies headache, nausea, vomiting, double vision, or change in vision. She, herself, did not admit to memory difficulty but when asked specifically, she did admit to that.

Tuesday, April 24, 2018—8:30 pm—53°F (12°C)—Overcast

Exactly five years ago, on April 24, 2013, Sumi had her appointment with the neurologist. That day the neurologist did a Physical Exam and asked questions about Sumi's past medical history, family history, personal history, and current medications.

The neurologist's review of Sumi's all-systems was unremarkable except for hearing loss in both ears, left worse than right. Hearing loss was familial in nature as members on her side of the family suffered from the same problem and Sumi had surgery in her left ear but it wasn't able to correct it.

I told the doctor that Sumi was born premature and her development milestones were slightly delayed but she had done well over the years and has been a normal active person. Up until 2009 she had worked at the Gap store and since then, has been a homemaker.

From the physical exam, the doctor found Sumi to be well developed, well nourished, and not in any acute distress. Her general examination was rather unremarkable. All her vital signs were normal.

Then the doctor performed some neurological exams. These involved asking Sumi questions to test her memory and recall. In one of the standard memory recall tests, the doctor asked Sumi to remember three words and then recall them. The doctor also asked her to perform simple additions and subtractions. Another test was to duplicate a drawn cube on a paper. And yet another was for Sumi to draw the face of a clock on a piece of paper and then fill in the hands of the clock to indicate the specific time the doctor requested.

Shown below is the report from Sumi's neurological exam:

She [Sumi] is aware and alert. Speech is fluent, but she is unable to provide me with details of her history. She gets easily frustrated when you ask her specifics. She, in fact, had trouble recalling the exact age of her siblings. She actually took a little time to remember their names also. She was unable to provide me with details of her children, as to which institute Jasen is studying and when he is going to graduate. She did recall that they were living in Los Angeles.

She was able to follow 2-step commands but cannot cross midline. She had mild left-right confusion. No frontal release signs were observed. Her recent memory registration was 0/3, but with repeated instruction, she was able to get 3/3. However, 5-minute recall was 0/3. With clues it was 1/3. She was unable to do simple addition and subtraction. She was also unable to copy a drawn cube.

Drawing the face of a clock took several minutes and several attempts. She had initially crowded all the numbers but ultimately was able to spread them out appropriately. But she was unable to put the hands where I asked her, to show the specific time. She felt that it was too difficult.

She was able to recall President Obama's name, but could not recall any past presidents or the current governor of Michigan or prime minister of India. She does follow a surgeon TV show and watches TV regularly but could not recall the name of the show and what it is about.

Cranial nerve examination revealed that the visual fields are full. Extraocular movements are intact without nystagmus. Facial sensation and movements are normal. No focal cranial nerve deficit noted. She does have bilateral hearing decrease.

Motor examination revealed that her gait is normal and narrow based. I did not see any bradykinesia or stooped posture. Outstretched hand did not reveal any pronator drift. Rapid movements are symmetrical. Finger-to-nose test was normal on the right and with minimal difficulty on the left, but there was not clear past pointing or dysmetria. It took me several attempts to ask her to perform the finger-to-nose testing.

Sensory examination was unremarkable to light touch and pinprick. Deep tendon reflexes were slightly brisk, but symmetrical, especially in her lower extremity, including ankle jerk, which is slightly brisk.

Wednesday, April 25, 2018—9:30 pm—44°F (7°C)—Clear night

I would like to continue sharing Sumi's initial doctor reports. Below is from the neurologist's first impression and plan:

Mrs. Mehta appears to be suffering from progressive cognitive difficulty in several domains without any clear-cut focal neurological deficits, except hearing decrease. The most likely diagnosis at this point is Alzheimer's disease, although other causes of dementia cannot be excluded.

Mrs. Mehta has undergone an EEG examination this morning (April 24, 2013) and an MRI a couple of days ago. I have reviewed both of them. The MRI shows mild generalized atrophy, but no clear focal lesions. In fact, MRI is quite unremarkable. Her EEG is also showing slight excessive theta activity, but is otherwise unremarkable.

I have also reviewed Mrs. Mehta's previous labs. Her lipid profile is unremarkable and so are her CBC, electrolytes, and LFTs. Her TSH has been checked on multiple occasions and has been normal. I could not find any B12 level or RPR. I would like to obtain both of those along with serum lactate today just as screening for mitochondrial disease, although, I do not believe that is the problem. I would also like to obtain FGD PET scan to look for a specific pattern of hypometabolism in Alzheimer's type of dementia or some other type of pattern, which may help us to steer away from a diagnosis of Alzheimer dementia. They are agreeable to that testing and this will be scheduled in the next few days.

Regarding the treatment of dementia, I would like to start her on Aricept 5 mg once a day for next month or so. After that, she would increase to 10 mg once a day. Side effect profile was discussed with her husband. We also discussed the safety related issues, financial transaction related issues, and general prognosis and expectation in Alzheimer's type of dementia. Not surprisingly, he became emotional after learning this and, actually, Mrs. Mehta herself tried to console him.

A few days later, on May 1, 2013, Sumi had a PET image of her brain done with tomographic images and an IV administration of 10.02 mCi of 18 FGD. The test found abnormal cerebral glucose metabolism study and showed a pattern most consistent with Alzheimer's disease. The hypometabolism seen in the parietal and temporal cortex were very classic for Alzheimer's disease.

April 24, 2013 was the saddest day of our lives.

When you suspect something is not right with your health, you seek medical advice from your primary care physician. When your primary care physician asks you to see an expert, your mind races and you start to suspect something is serious. After a few tests, when the medical expert confirms your worse fears, it becomes a life changing event. You know things will never be the same. It robs the life of many shared hopes and dreams.

On hearing the neurologist's diagnosis that Sumi has Alzheimer's disease, the first thing that went through my mind was that, maybe, the doctor wasn't 100% certain. Maybe Sumi just had memory issues due to poor hearing. But then, the next thought racing through my mind was,

“Why her? Why Sumi?” Especially because the disease is not related to one’s lifestyle. It’s beyond anyone’s control.

At that time, I didn’t have a full understanding of what the disease would do to Sumi. But knowing the little I did about what Alzheimer’s disease does to a person I was devastated. Sumi, in her innocent, positive, and compassionate way was more concerned about seeing me cry. She tried to console me and didn’t think about the full gravity of her own health and what it would do to her as time passed.

Driving home from the doctor’s office was the worst driving of my life. I was fighting tears while trying to focus on the road. I stayed in the same slow lane and tried not to show any overt and raw emotions as I did not want Sumi to get concerned and feel bad.

Thank you all for your kind responses. I would like to share some of them below:

KC, truly it’s remarkable. Truly no words can do justice to your experience and journey with Sumi and the kids. After reading in depth the details we can only say hats off to all of you and our love for all you is endless.

-A friend, from Bloomfield Hills, Michigan

Oh, my lord to comprehend this to understand the life itself. You are a unique lover...Your devotion to this love speaks volumes of your character and upbringing. I am the luckiest man to know you. There is no doubt of your strength but seeing the strength of Sumi after knowing what happened and consoling you is testimonial to her unending purity of love for you. If tears are the language then I am speaking that today!

-A friend from California

KC, I salute you for how you take care of her. I have seen you getting emotional. Wish we can do something but feel helpless. I always think of what Sumi must be going through. God bless both of you...Don't think you are alone in this. We are by you.

-A friend from Oakland Twp., Michigan

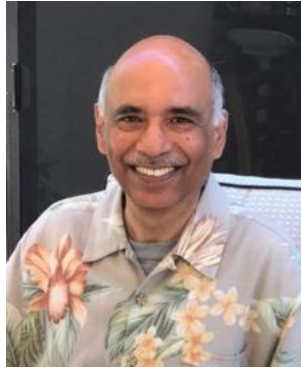
As a professional who had to give bad news to many families and seeing their reaction and often sharing their grief, I must say you come out as a very unique partner. Hats off to you for your love, caring, sacrifice, and devotion.

-A retired neurosurgeon from Jackson, Michigan

Dear KC, I read all your posts at least once and most of them a couple of times. I find it motivating, encouraging, and it pushes me to be a better person. It is really amazing how you take all of us on a journey through your troubles and difficulties without making any of us feel inadequate or uncomfortable. It reminds me of our Rough Water Raft tour in Alaska. Everybody on the raft experienced the turbulent waters, but all felt safe and secure because a tour guide—like you—made it so! Thank you for sharing your life with us...God bless you, Sumi-ben and all of the people that help and support you.

-A friend from Bloomfield Hills, Michigan

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.