

My Journey with Sumi

COLLECTION OF ESSAYS —
FEB 14.2013 TO APR 27.2021

MY JOURNEY WITH SUMI

First, I must acknowledge the people that care deeply for me and Sumi.



Peggy



Selina



Kailash

Without their professionalism and love, Sumi's Journey would be much different.

MY JOURNEY WITH SUMI

A collection of 25+ essays.

All essays are stand-alone by themselves and can be read individually.

In 2013, at age 59, my wife Sumi was diagnosed with younger onset Alzheimer's disease. I had been happily married to Sumi for more than 40 years but done little caregiving. I hoped for a misdiagnosis, read all the books I could and 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's behavior then I realized I needed to change to best meet Sumi's needs.

I first wrote formally about Sumi's disease in 2015 and with the encouragement of confidants, I continue writing a WhatsApp journal called, "My Journey with Sumi". It allows me to channel my feelings, document changes, and share a glimpse into our lives with close family and friends. I write "in the moment" without much dwelling on it or fine tuning, to help process my emotions. I find it therapeutic.

[Sumi's Bowel Movement](#) is the latest essay.

MY JOURNEY WITH SUMI

ESSAY #28

Sumi's Bowel Movement

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I'm Here to Help You on Your Loved One's Journey

01 Inspiration

INSPIRATION

**“If you can’t measure it,
you can’t improve it.”**

PETER DRUCKER

INSPIRATION

**“If you can’t measure it,
you can’t improve it.”**

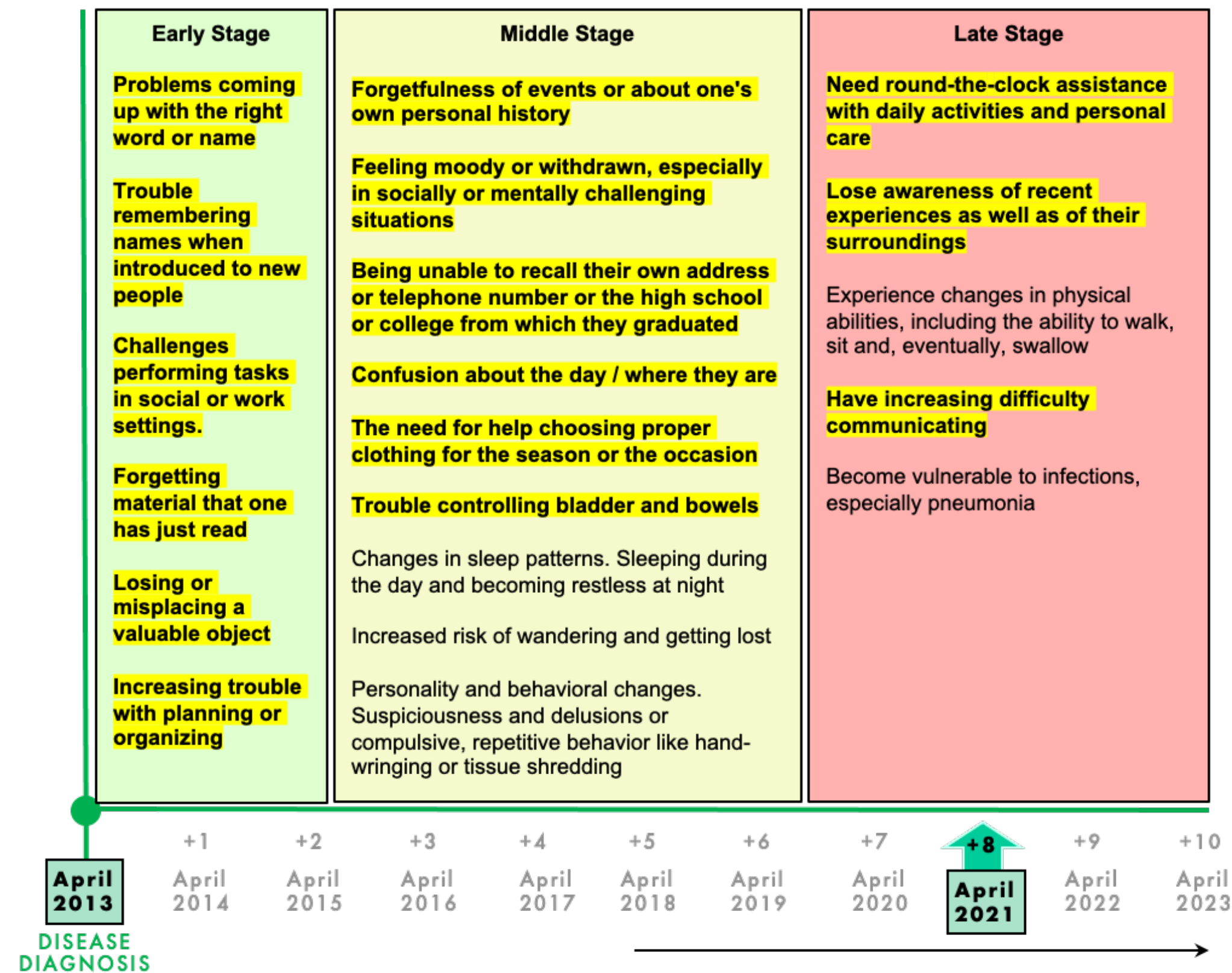
PETER DRUCKER

As a mechanical engineer, in the college we studied design and working of the Internal Combustion (IC) engines. Like any well-tuned machine, we studied the efficiency of the IC engine by its input (gasoline or diesel) and its output (exhaust gases). You can tell a lot about the IC engine by studying the exhaust gases. For example, the exhaust gases are mainly of two types: inoffensive and pollutants contaminants. The first are Nitrogen, Oxygen, Carbon Dioxide, water vapor and Hydrogen. The Pollutants are mostly Carbon Monoxide, Hydrocarbons, Nitrogen Oxides and Lead. One of the main aspect of a well-tuned engine is air to fuel ration. Too much air and low fuel makes engine under performs where as rich fuel and low air produces more pollutants because of incomplete combustion.

02 Sumi's 9th Year of the Disease

9th Year of Alzheimers

Sumi exhibits behaviors highlighted in yellow



* Source: Alzheimer's Association

STAGE 3

Sumi is in the late stage of her disease per Alzheimer's Association's 3-stages.

ROUND-THE-CLOCK CARE

Sumi needs assistance with her daily activities and personal care. She cannot go to toilet by herself for her BM. She wears sanitary briefs (diapers).

A NEW CHALLENGE EMERGES

In 2018 and 2019, Sumi's Bowel Movement (BM) did not follow any pattern.

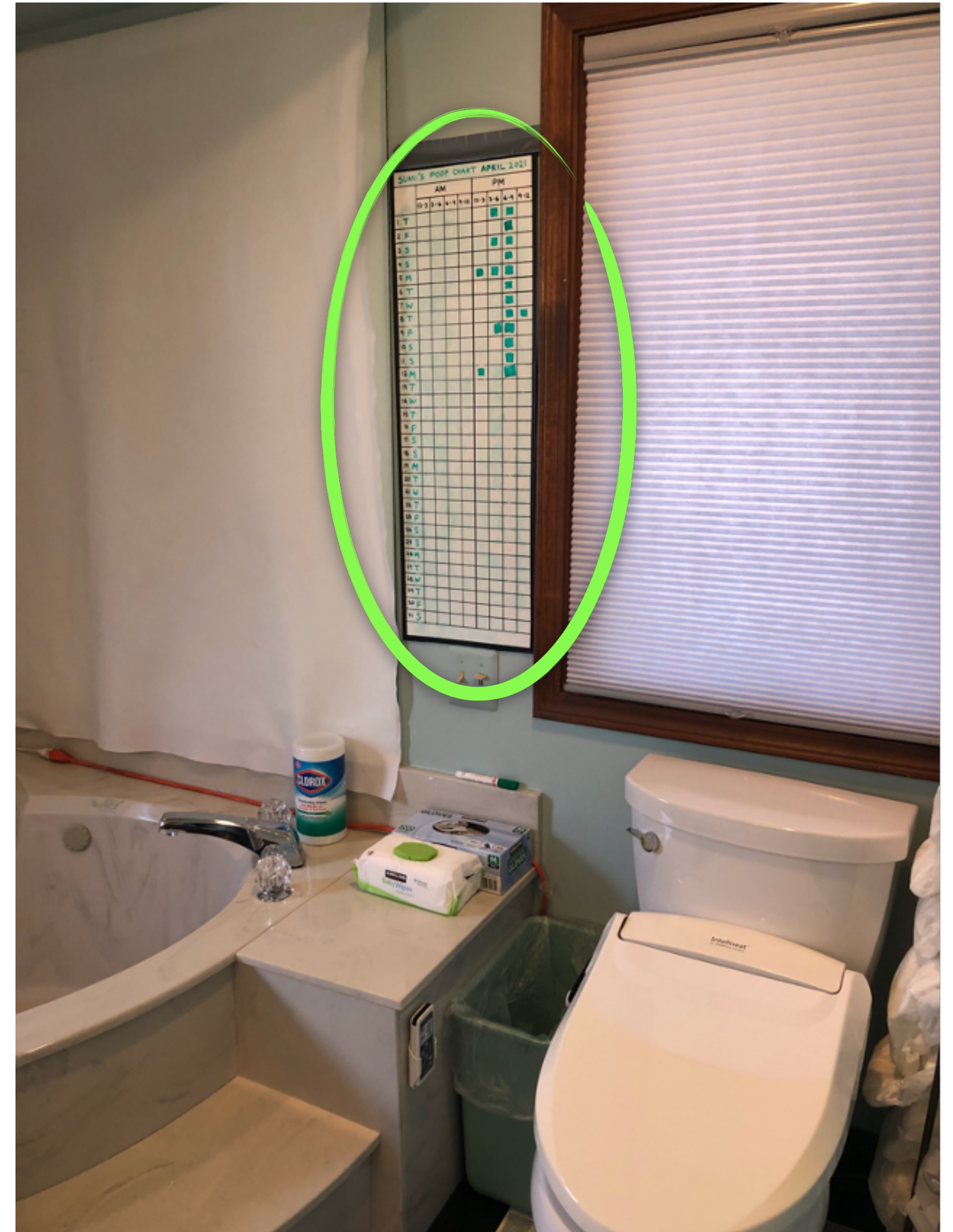
About half the time she would have BM in the middle of the night which required cleaning and changing her.

This disrupted our sleep.

03 Charting Method & Control Data

Fast forwarding...

- Since Sumi was not able to verbally express her needs, discomfort or pains, as her caregiver, I managed different types of input and output. She did not eat by herself and her food was prepared based on what I thought would be the best well-balanced meal for her.
- From early 2018, I began monitoring her BM as her food intake was fairly regular but output wasn't.
- BM monitoring also served as a good tool to communicate with Sumi's primary care physician (PCP).
- As shown in the photo, I crafted a white board chart to capture her BM on a monthly basis. Every BM is noted on the board with a solid square to indicate the day and time of her BM.



Data Charting

BM CHARTED ON 24-HR CYCLE

AM (12:00 am to 11:59 am)

PM (12:00 pm to 11:59 pm)

PATTERNS DEVELOPED

BM was (almost) equally divided between AM and PM.

Morning BM's fell between 3am and 6am.

CLEANING & CHANGING

Early morning cleaning disrupted her sleep and we had trouble falling back to sleep.

Size of Square = Quantity of BM

2018	AM				PM			
	12-3	3-6	6-9	9-12	12-3	3-6	6-9	9-12
SUN 9/30		■				■		
MON 10/1		■						■
TUE 10/2						■		■
WED 10/3		■						■
THU 10/4			■			■		■
FRI 10/5		■	■		■		■	
SAT 10/6					■		■	

04 Call to Action

OH NO!

**On October 8th, 2018, a very warm day,
Sumi was walking with us in the Rochester Park.**

**She side stepped on the edge of a concrete walk-way
and twisted her right foot causing
a hairline fracture in her ankle.**

6 weeks of Recovery

- Sumi had to wear a removable boot.
- She was moved around the house and outside the house in a wheel chair.
- After the 6 weeks, she was back on her feet and resumed walking again.



NEW BM PATTERNS

However, during recovery, she slowly reduced her eating to only a small quantity of food.

With no intake, there was no output.

On two occasions we had to take her to the Emergency Room to receive an enema to extract BM.

BM Data during Recovery

OCT 2018

Early Morning BM = 10
Evening BM = 16

The grid shows BM data for October 2018. A yellow horizontal bar highlights the period from October 8th to 17th, corresponding to the patient's fracture and hospitalization. A blue bracket on the right side of the grid spans from October 18th to 27th, indicating ER visits and an enema. A green bar at the bottom of the grid, starting on November 20th, indicates the cast was removed.

OCT 8, 2018
SUMI FRACTURES
HER ANKLE

OCT 18 & 27
ER VISITS
ENEMA

NOV 20
ANKLE HEALED
CAST REMOVED

NOV 2018

Early Morning BM = 4
Evening BM = 4

The grid shows BM data for November 2018. A green horizontal bar highlights the period from November 20th to 27th, corresponding to the cast removal and recovery period.

DEC 2018

Early Morning 18
Evening 10

The grid shows BM data for December 2018, which is faded. It displays BM frequency for the month, with early morning counts of 18 and evening counts of 10.

EFFECTS ON SUMI'S BM

After 6 weeks, Sumi lost ~25 lbs.

I feared her decline would not be reversible.

She began eating more food but it took another week for her BM to come back to her pre-fracture status.

BM Data during Recovery

OCT 2018

Early Morning **10**
Evening **16**

Day	BM Count
Oct 1	0
Oct 2	0
Oct 3	0
Oct 4	0
Oct 5	0
Oct 6	0
Oct 7	0
Oct 8	10
Oct 9	0
Oct 10	0
Oct 11	0
Oct 12	0
Oct 13	0
Oct 14	0
Oct 15	0
Oct 16	0
Oct 17	0
Oct 18	16
Oct 19	0
Oct 20	0
Oct 21	0
Oct 22	0
Oct 23	0
Oct 24	0
Oct 25	0
Oct 26	0
Oct 27	16
Oct 28	0
Oct 29	0
Oct 30	0
Oct 31	0

OCT 8, 2018
SUMI FRACTURES
HER ANKLE

OCT 18 & 27
ER VISITS
ENEMA

NOV 20
ANKLE HEALED
CAST REMOVED

NOV 2018

Early Morning **4**
Evening **4**

Day	BM Count
Nov 1	0
Nov 2	0
Nov 3	0
Nov 4	0
Nov 5	0
Nov 6	0
Nov 7	0
Nov 8	0
Nov 9	0
Nov 10	0
Nov 11	0
Nov 12	0
Nov 13	0
Nov 14	0
Nov 15	0
Nov 16	0
Nov 17	0
Nov 18	0
Nov 19	0
Nov 20	4
Nov 21	0
Nov 22	0
Nov 23	0
Nov 24	0
Nov 25	0
Nov 26	0
Nov 27	0
Nov 28	0
Nov 29	0
Nov 30	0

DEC 2018

Early Morning **BM = 18** Evening **BM = 10**

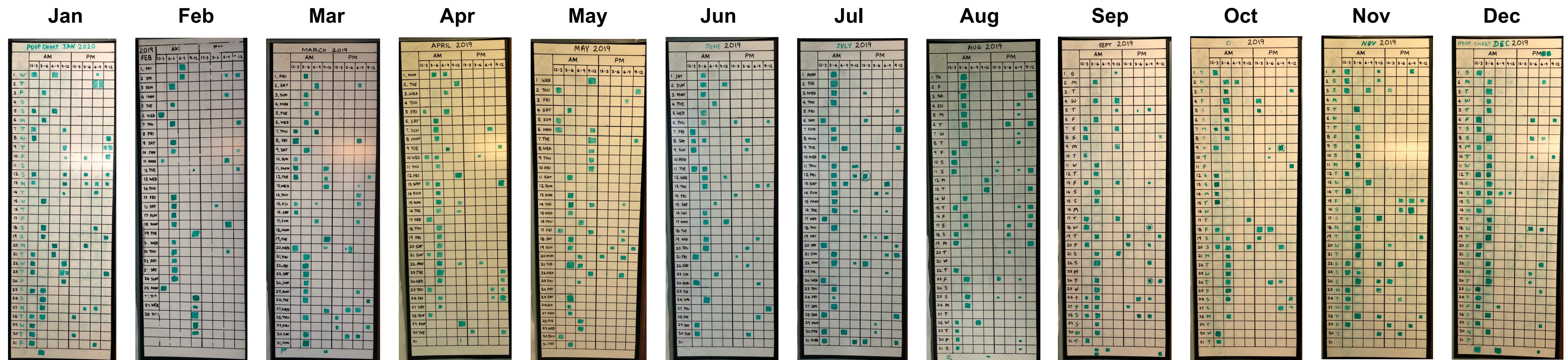
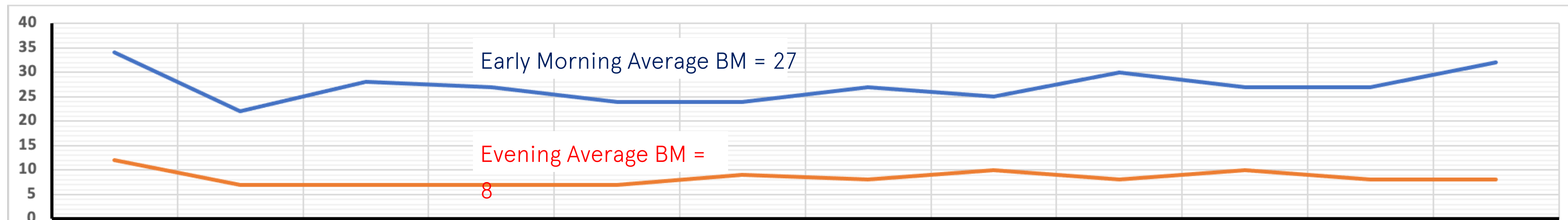
Day	BM Count
Dec 1	0
Dec 2	0
Dec 3	0
Dec 4	0
Dec 5	0
Dec 6	0
Dec 7	0
Dec 8	0
Dec 9	0
Dec 10	0
Dec 11	0
Dec 12	0
Dec 13	0
Dec 14	0
Dec 15	0
Dec 16	0
Dec 17	0
Dec 18	0
Dec 19	0
Dec 20	0
Dec 21	0
Dec 22	0
Dec 23	0
Dec 24	0
Dec 25	0
Dec 26	0
Dec 27	0
Dec 28	0
Dec 29	0
Dec 30	0
Dec 31	0

AGAIN...NEW BM PATTERNS EMERGE

This pattern of more BM in the Early Morning and less in the Evening continued in 2019.

BM Data (daily) - 2019 Calendar Year

Morning	34	22	28	27	24	24	27	25	30	27	27	32
Evening	12	7	7	7	7	9	8	10	8	10	8	8
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec



HOW MIGHT WE...

I began to experiment, how might we influence her BM Patterns from Early Mornings to Evenings?

05 Experiment Data

INPUT TO OUTPUT

Step 1: Let's Normalize Sumi's Diet

Bulk Prepared and Individually Portioning



FRESH VEGETABLES



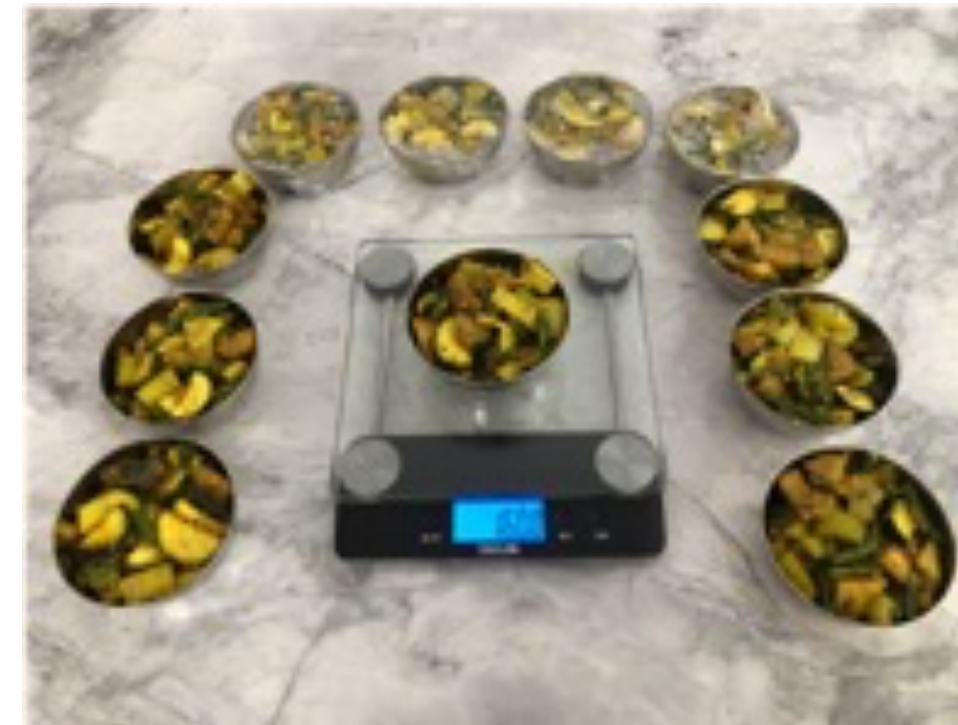
RAW VEGETABLES PLATTER



DAILY PORTION
FRESH VEGETABLES



COOKED VEGETABLES



DAILY PORTION
COOKED VEGETABLES



SMOOTHIE

- Raspberries
- Blackberries
- Blueberries
- Watermelon
- Pineapple
- Dates

Deleted bananas from the smoothie₂₇

Daily Food Intake (1.43 kg = 3.14 lbs.)

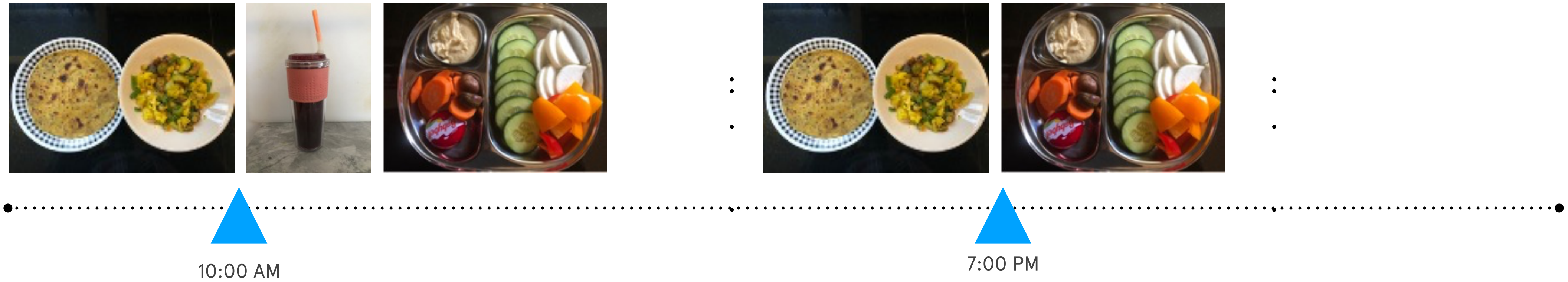
Food Items	Morning (9 am)	Afternoon (2 pm)	Evening (5:30 pm)
Pan fried, spiced vegetables Zucchini squash, green beans, eggplants, celery, onions, cauliflowers & chick peas Methi Paratha (Lightly spiced Indian flat bread with fenugreek leaves)	230 grams		230 grams
Mixed-Berries Smoothie (100 grams of raspberries, blackberries and blueberries) with dates, fresh watermelon and pineapples	350 grams		
One boiled egg and ½ apple	95 grams		
Cold vegetables plate (Carrots, bell peppers, cucumbers, radishes, cherry tomatoes) with hummus and cheese		260 grams	260 grams
Liquid: Sumi hardly drinks water. We give her water melon pieces. Her food has very high water content so she is well hydrated and her urination quantity is abundant and of no concern	Daily Food Intake 1.43 kg. = 3.14 lbs.		
Medications: Sumi is in excellent physical shape. She does not require any medications. She used to take Aricept and Namenda until 2018 and then I stopped as there was not benefit. I occasionally give her a small dose of OTC sleeping pill			

INPUT TO OUTPUT

Step 2: Let's Adjust Eating Times

Bulk Prepared & Individually Portioning

BEFORE JUNE 2020

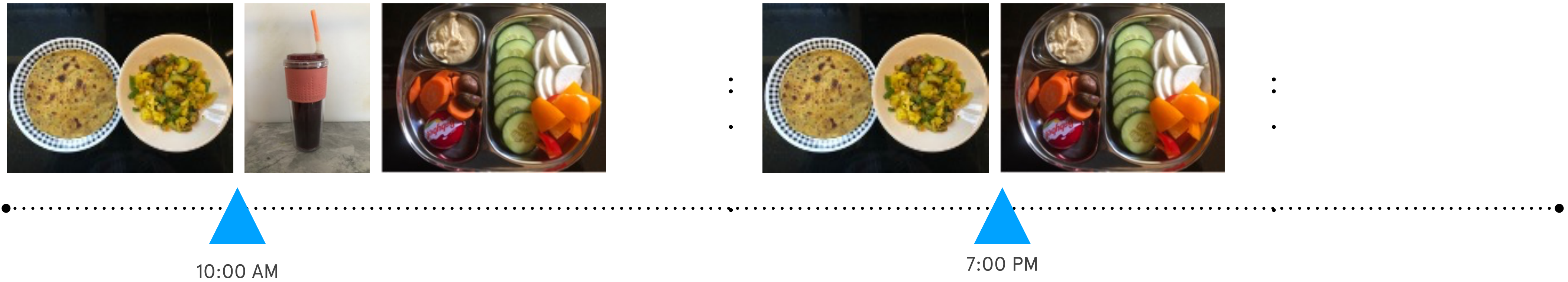


AFTER JUNE 2020



Bulk Prepared & Individually Portioning

BEFORE JUNE 2020



AFTER JUNE 2020



INPUT TO OUTPUT

Step 3: Let's Adjust Her Daily Physical Activities

Sumitra Mehta's IDALs (Instrumental Activities of Daily Living)						
March 13, 2021						
Daily Activities for 24 Hour Cycle	Estimated time of the day	Hours of Assistance Needed (Estimated Average)			Comments	
		Daily (Averages)	No of Days per week	Total Hours per		
Getting out of bed	8:30 am - 8:45 am					
Food Preparation	8:45 am - 9:00 am					
Feeding	9:00 am - 10:00 am					
batting/hygiene	10:00 am - 10:30 am					
Dressing/Grooming	10:30 am - 11:00 am					
Walking	11:00 am - 12:00 pm					
Light Cleaning/Laundry	12:00 pm - 1:00 pm					
Morning Activities and Assisted Hours						
Sumitra Mehta's IDALs (Instrumental Activities of Daily Living)						
March 13, 2021						
Daily Activities for 24 Hour Cycle	Estimated time of the day	Hours of Assistance Needed (Estimated Average)			Comments	
		Daily (Averages)	No of Days per week	Total Hours per		
Resting	1:00 pm - 4:30 pm					Person with Alzheimer's disease do not follow a particular regimen or a routine, however, Sumitra rests for about 3 to 4 hours in the afternoon in a lounge chair in a room with an outside view through the window. During these 3 to 4 hours of resting, she also naps frequently. Since I am (her husband) is at home, I can supervise her resting without requiring any caregivers. I feed her lunch of cut vegetables around 2 pm.
Diaper Change	4:30 pm - 4:45 pm	0.25	7	1.75		Sumitra normally wets her diaper after the rest requiring a change of diaper.
walking / pacing in foyer	4:45 pm - 5:30 pm	0.75	7	5.25		After Sumitra has had enough rest, we try to keep her on her feet so she can get tired, digest her food and could fall asleep in the night with ease.
Feeding	5:30 pm - 6:30 pm	1	7	7		Just as in morning, some days Sumitra sits in a chair to get fed and some days she likes to be on her feet and get fed while she is moving on her feet.
Supervised walking in the basement	6:30 pm - 8:00 pm	1.5	7	10.5		After dinner, Sumitra is kept on her feet so she gets to digest her food, get tired and thereby could fall asleep with ease in the night.
Toileting/hygiene/ Change of clothes	8:00 pm - 8:30 pm	0.5	7	3.5		Sumitra resists being changed. She screams loudly when her pants are pulled down (I guess, no one would like their pants pulled down by others!). Sumitra's bowel movements are regular (between 6:30 pm and 8:00 pm). I chart her bowel movement so monitor her excretion.
Walking in foyer	8:30 pm - 9:30 pm	1	7	7		Sumitra's walk continues for the same reason that she can digest her food, get tired and could fall asleep with ease in the night.
Evening Activities and Assisted Hours						
Go to bed (Sleeping)	9:30 pm - 8:30 am					On most nights, Sumitra sleeps well. I check on her one or two times in the night and change her if required. There are some night when she cannot fall asleep or wakes up in the middle of the night with energy. I sometimes walk her and then she goes back to sleep.
Night						
Daily / Weekly Instrumental Activities and Assisted Hours						
		9	7	63		

Sumi's Log of Instrumental Activities of Daily Living (IADLs)

INPUT TO OUTPUT

Step 3: Let's Adjust Her Daily Physical Activities

Sumitra Mehta's IDALs (Instrumental Activities of Daily Living)							
March 13, 2021							
Daily Activities for 24 Hour Cycle	Estimated time of the day	Hours of Assistance Needed (Estimated Average)			Comments		
		Daily (over a week)	No. of Days	Total Hours per			
Sumitra Mehta's IDALs (Instrumental Activities of Daily Living)							
March 13, 2021							
Getting out of bed	8:20 am - 8:45 pm						
Food Preparation	8:45 am - 9:00 pm						
Feeding	9:00 am - 10:00 pm						
bathing/hygiene	10:00 am - 10:30 am	Diaper Change	4:30 pm - 4:45 pm	0.25	7	1.75	Sumitra normally wets her diaper after the rest requiring a change of diaper.
		walking / pacing in foyer	4:45 pm - 5:30 pm	0.75	7	5.25	After Sumitra has had enough rest, we try to keep her on her feet so she can get tired, digest her food and could fall asleep in the night with ease.
		Feeding	5:30 pm - 6:30 pm	1	7	7	As in morning, some days Sumitra sits in a chair to get fed and some days she likes to be on her feet and get fed while she is moving on her feet.
Dressing/Grooming	10:30 am - 11:00 am	Supervised walking in the basement	6:30 pm - 8:00 pm	1.5	7	10.5	After dinner, Sumitra is kept on her feet so she gets to digest her food, get tired and thereby could fall asleep with ease in the night.
		Tolerating/hygiene/Change of clothes	8:00 pm - 8:30 pm	0.5	7	3.5	Sumitra resists being changed. She screams loudly when her pants are pulled down (I guess, no one would like their pants pulled down by others!). Sumitra's bowel movements are regular (between 6:30 pm and 8:00 pm). I chart her bowel movement so monitor her excretion.
Walking	11:00 am - 12:00 pm						
Light Cleaning/Laundry	12:00 pm - 1:00 pm						
Morning Activities and Assisted Hours							
Evening - IDALs (Instrumental Activities of Daily Living)							
Walking in foyer	8:30 pm - 9:30 pm	1	7	7		Sumitra's walk continues for the same reason that she can digest her food, get tired and could fall asleep with ease in the night.	
Evening Activities and Assisted Hours		5	7	35			
Night							
Go to bed (Sleeping)	9:30 pm - 8:30 am	Assistance Not Required	N/A	N/A		On most nights, Sumitra sleeps well. I check on her one or two times in the night and change her if required. There are some night when she cannot fall asleep or wakes up in the middle of the night with energy. I sometimes walk her and then she goes back to sleep.	
Daily / Weekly Instrumental Activities and Assisted Hours		9	7	63			

Sumi's Log of Instrumental Activities of Daily Living (IADLs)

3 Segments:

12 hours
in bed

6 hours
seated in a chair

6 hours
on her feet (walking/pacing)

Activities of Daily Living (ADLs)

BEFORE JUNE 2020

- Walk in basement for 1.5 hours in the Morning
- 2 meals nine hours apart. Breakfast 10am, Dinner 7pm

AFTER JUNE 2020

- No walking in the Morning. ~6hrs of sitting. Mid-day cold vegetables plate (while seated in chair)
- Early dinner at 5:30pm. More walking after dinner allowing her to do her BM

Before June 2020																								
AM			PM											AM										
9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	
Wake up Get ready	Breakfast seated in the chair	Walk in the basement	Rest in chair					Walk, pace in the House	Dinner while on her feet	Walk, pace	Go to bed. Sleep-wake cycle but stay in bed One or two cleaning and changing													
Wake up Get ready	Breakfast seated in the chair	Rest in Chair			Eat Cold Veg (Seated)	Rest in chair	Walk, pace in the house/base ment	Dinner while on her feet	Walk, pace in the house/basement Have Bowel Movement	Go to bed. Sleep-wake cycle but stay in bed No cleaning. Sometimes change only.														
After June 2020																								

IMPROVEMENTS

**With changes in her diet, the timing of her food,
making her walk longer in the evening
and with some unexplained luck,
her BM gradually moved completely to in the evening!**

BM Data - September 2020 to January 2021

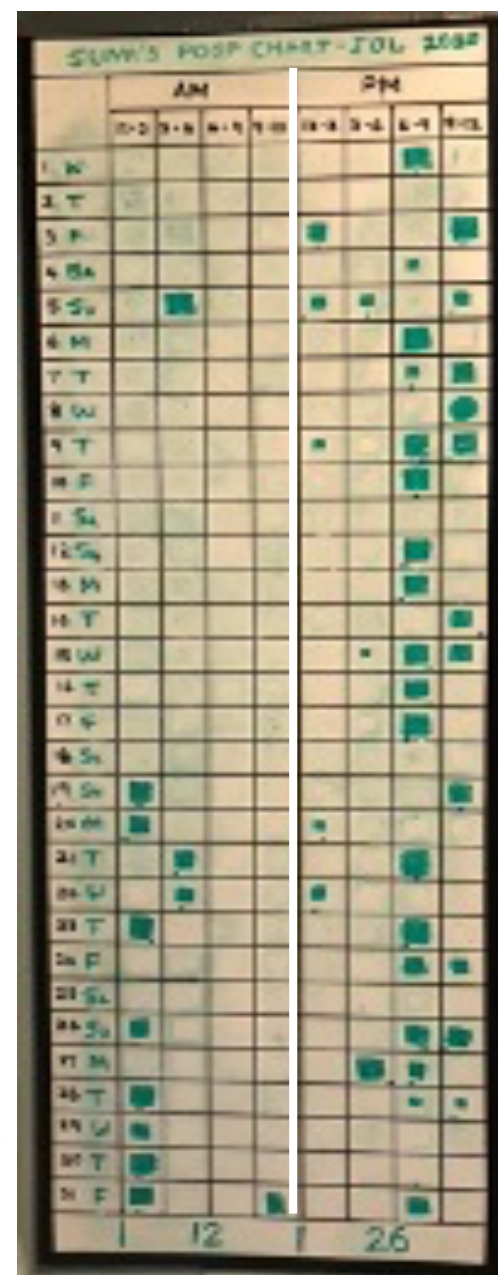
JUN 2020

Early Morning **18**
Evening **12**



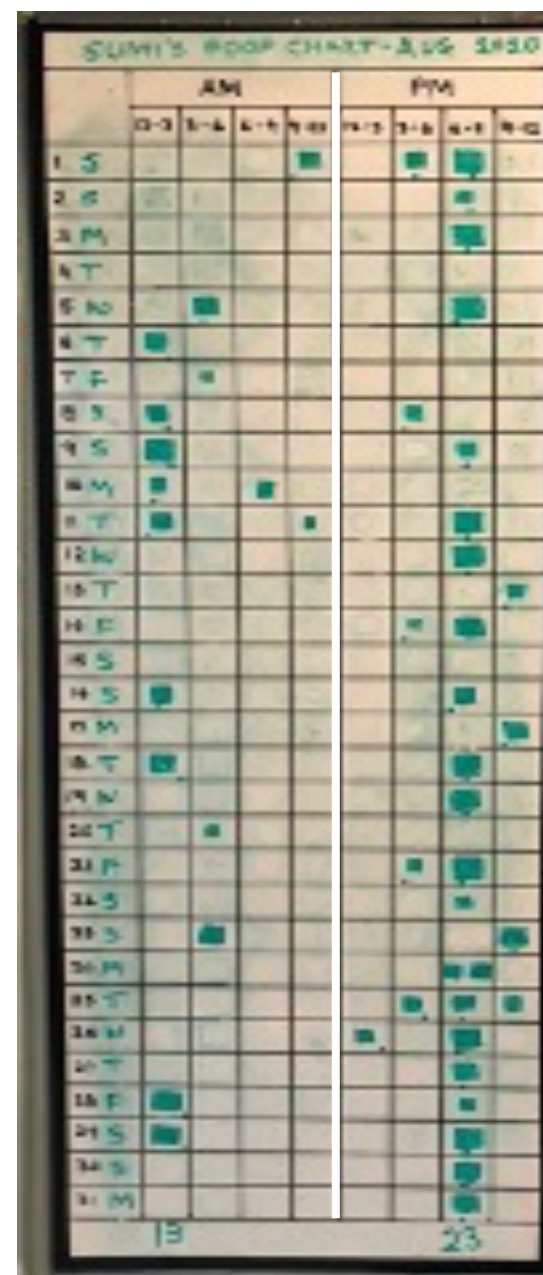
JUL 2020

Early Morning **12**
Evening **26**



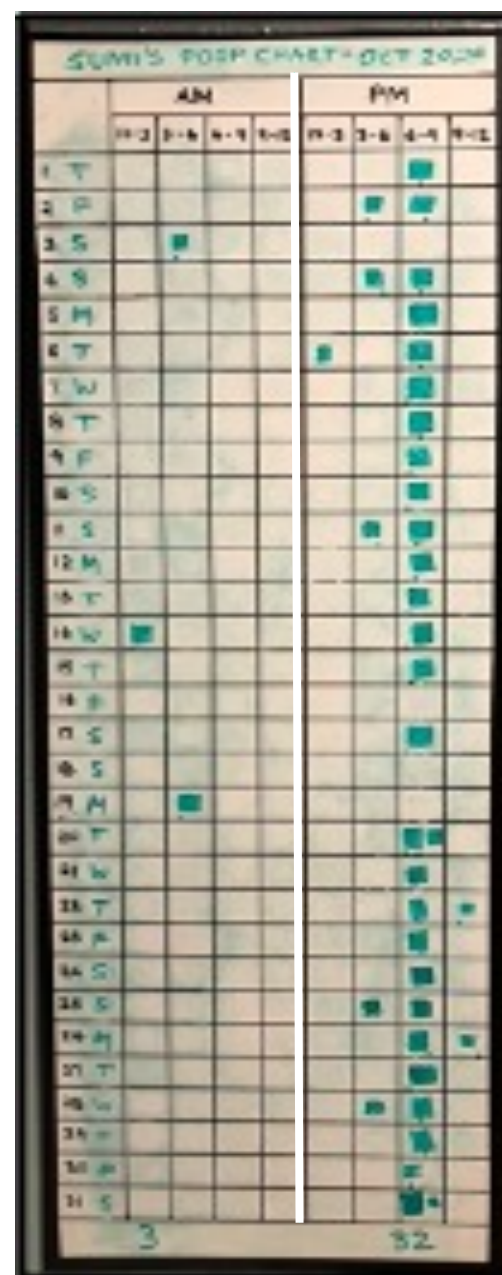
AUG 2020

Early Morning **13**
Evening **23**



SEP 2020

Early Morning **3**
Evening **30**



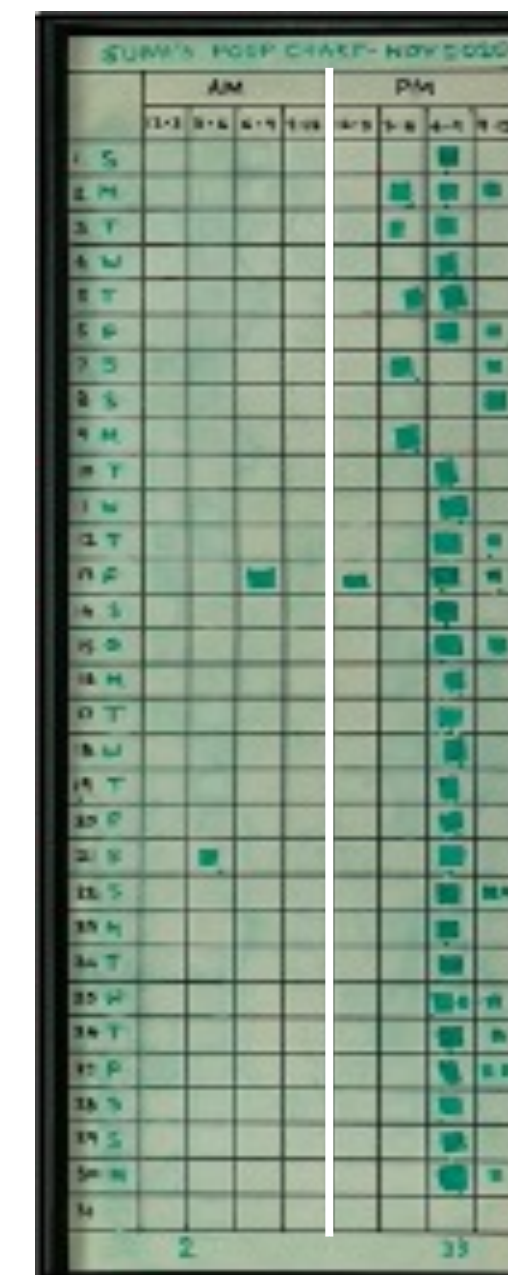
OCT 2020

Early Morning **3**
Evening **32**



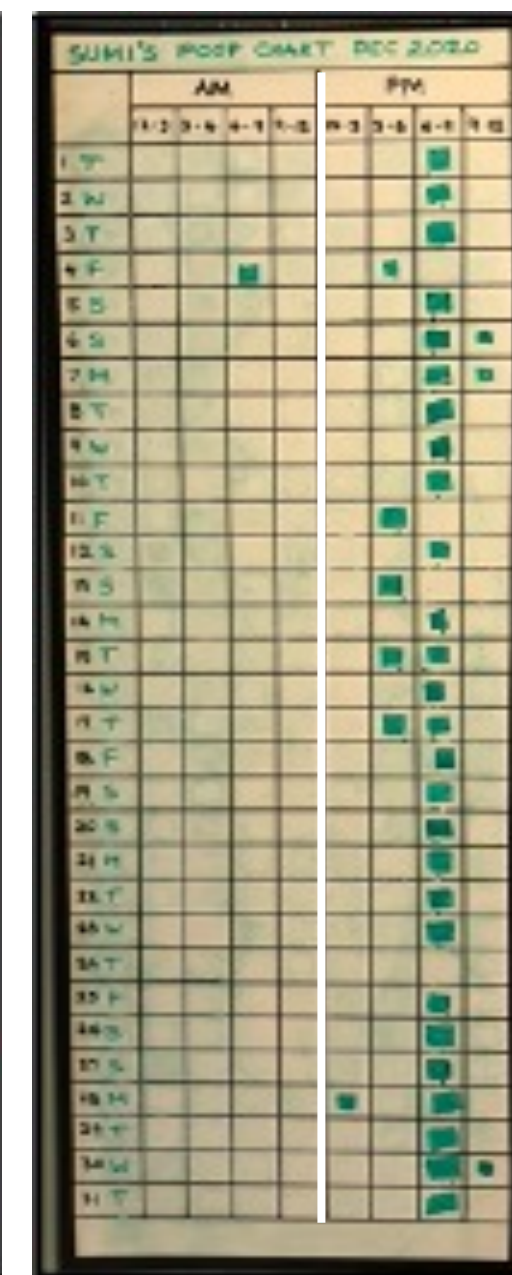
NOV 2020

Early Morning **2**
Evening **33**



DEC 2020

Early Morning **1**
Evening **31**



JAN 2021

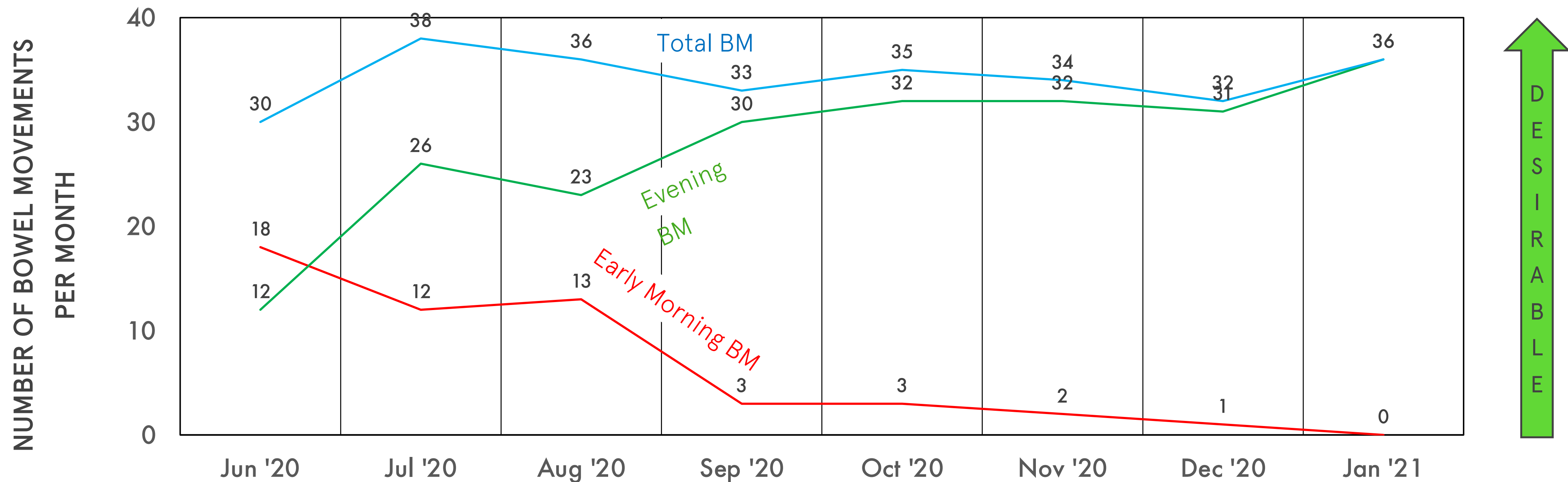
Early Morning **0**
Evening **36**



BM Data - September 2020 to January 2021

THE GRAPH BELOW SHOWS THAT OVER THE 7 MONTHS PERIOD:

- Evening BM kept rising from 12 to 36 (the green line)
- Early Morning BM declined from 18 to Zero (the red line)
- Total Numbers of BM ranged from 30 to 38 per month (the blue line), which approximates to 1 BM per day



06 Take Aways

TAKE AWAYS & LESSONS LEARNED

Thank you Peter Drucker – your management principles worked.

Sumi's BM habits showed a vast improvement by measuring (plotting) it over the last few years.

Sumi's Bowel is emptied before she goes to sleep and she is tired by being on her feet for about 6 hours prior to sleep.

With this fine-tuned, clock-work like schedule, Sumi has been sleeping well.

With a good night's sleep, Sumi's day starts well as she is more relaxed.

This Relaxed State has contributed to reduced anxiety and agitation in her.

I have been sleeping better as I don't have to clean and change her in the middle of the night.

TAKE AWAYS & LESSONS LEARNED

This small victory makes me feel good knowing I was able to change Sumi's habits during the late stage of her disease, which is very unusual.

We were able to affect these changes as Sumi is getting one-on-one, person-centered care at home.

Another lucky enabler was: Sumi is not on any medications so we do not have to deal with the side effects of medications, such as, diarrhea, drowsiness affecting her walks, etc.

Vijay, my chef friend of many years, has a saying, "Recipes Don't Make Chefs." I don't have a recipe for others to follow for what I did to change Sumi's BM habits. As evident from this presentation, it was experimenting with Sumi's diet, timing of the diet, sleep/rest/walking routine and deciphering her non-verbal cues. Like any complicated dish with many ingredients and spices, the chef's magic brings out the best. Desiring any change in your loved ones, imagine you are a chef who has collected all the ingredients and the data, now you have to inject your magic to get the needed changes.

TAKE AWAYS & LESSONS LEARNED

I know that this finely calibrated BM habits of Sumi will change as her disease progresses. In our Journey, there are many new normal and I take this as another new normal which I know will end at some point. But, I am grateful that it is happening. When new challenges come along, I will study, measure and analyze them to design solutions and mitigate them as best as I can.

**Finally, everyday, I get my free smell test (from Sumi's BM)
and get assured that I don't have Covid!**

07 Closing Thoughts

**And, when you want something,
all the universe conspires in helping
you achieve it!**

Paulo Coelho, The Alchemist



Thank you