



OUR ALZHEIMER'S JOURNEY – A CAREGIVING LOVE STORY

Kanu C (KC) Mehta
kanu.mehta@gmail.com

Chai & Business sponsored by Cogent
Farmington Hills Manor
23666 Orchard Lake Road, Farmington Hills, MI 48336
Wednesday, September 3, 2025
6:30 – 7:30 pm



This presentation is on my website – My Journey with Sumi

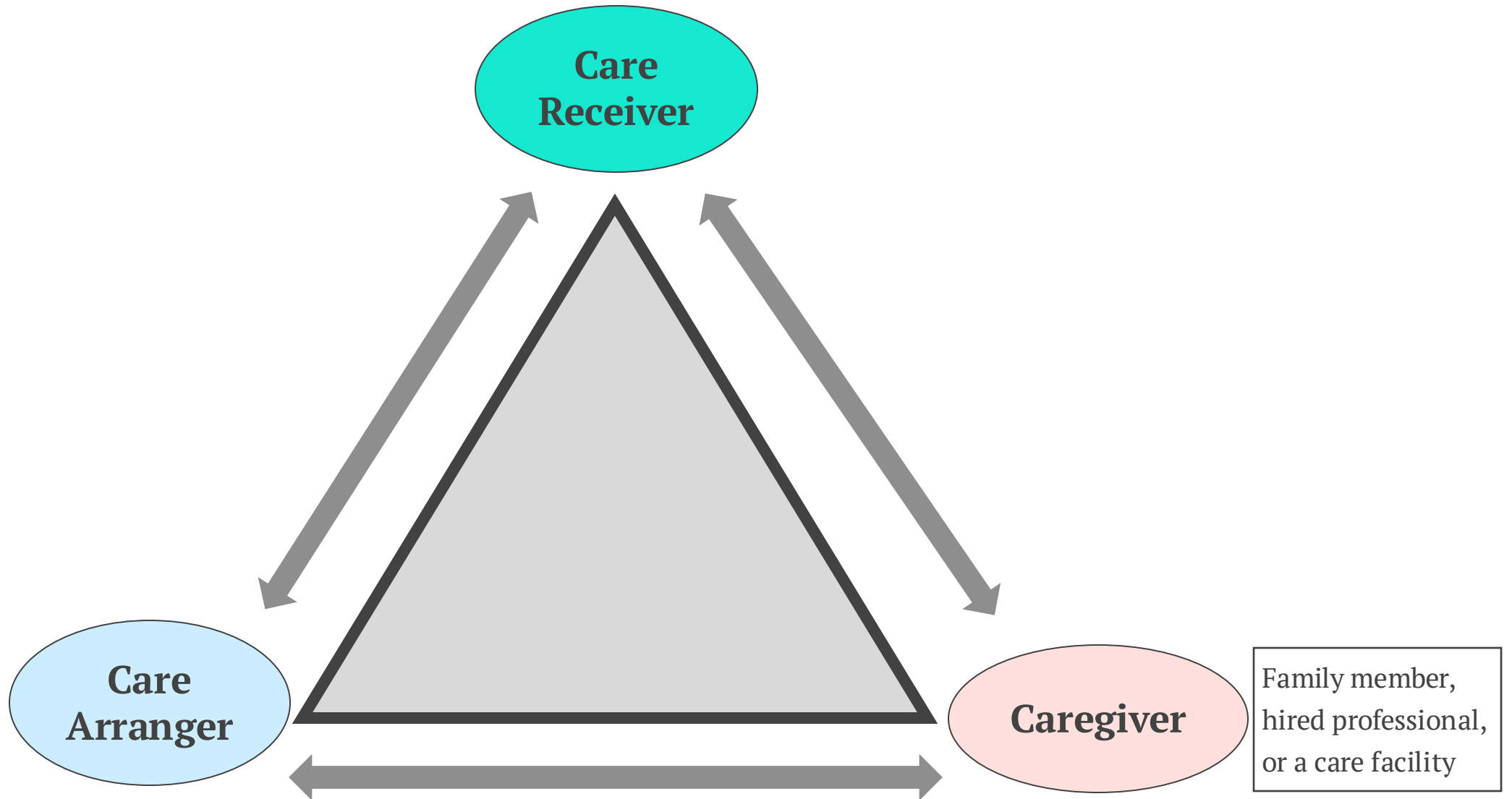


“

*There are only four kinds of people in the world:
those who have been caregivers,
those who are currently caregivers,
those who will be caregivers,
and those who will need caregivers.*

”

Rosalynn Carter (First Lady to President Jimmy Carter)





Agenda

Dementia:

1. What It Is
Facts and Figures

My Journey with Sumi:

2. Introduction
3. Emotional Roller Coaster
Mixed Emotions, Grieving Process, and Acceptance
Self Care
4. Creative Problem Solving for Sumi's Safety and Well-being
5. Closing Thoughts and Lessons Learned



What Is Dementia?

Loss of cognitive functioning, serious enough to interfere with daily functioning

Causes changes in:

- Memory
- Language
- Executive function (planning, organizing, and attention)
- Visual spatial skills
- Judgement / reasoning
- Personality / mood



Risk Factors:

That can't be changed include:

- Age
- Family history
- Down Syndrome

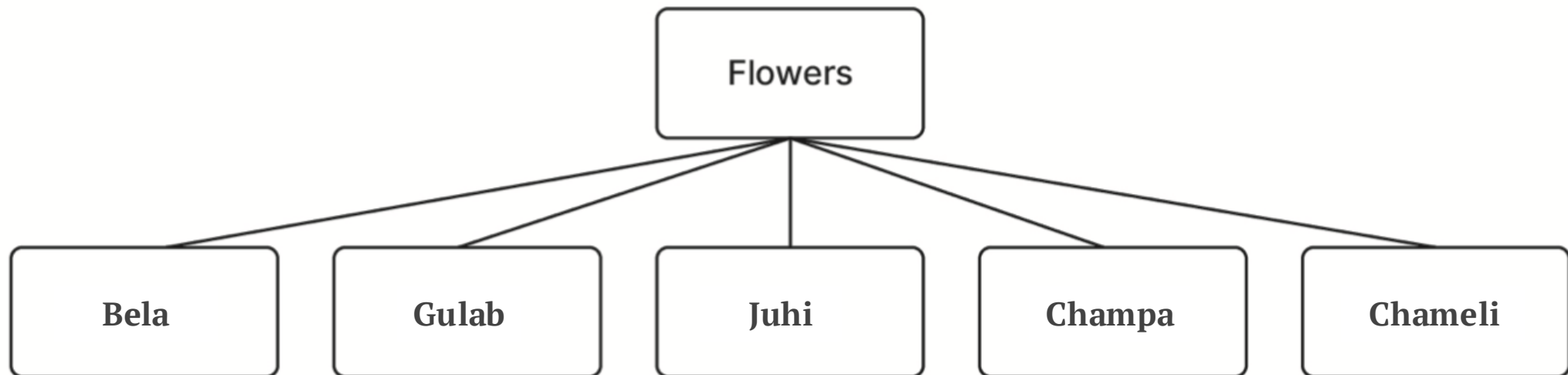
Controllable risk factors:

- Diet and Exercise
- Head trauma
- Stress & Sleep disturbances & Depression
- Excessive alcohol use
- Cardiovascular preconditions & Diabetes
- Vitamin and nutritional deficiencies
- Certain medications can worsen memory



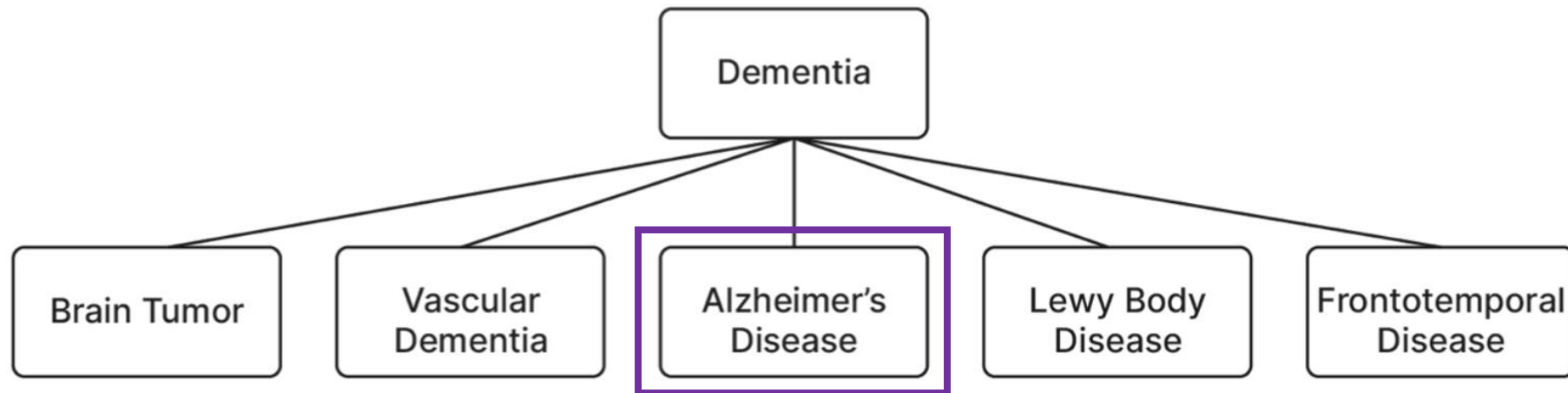
Dementia and Flower Metaphor

Flower is the Generic Name for Various Types of Flowers



Major Types of Dementia

Like Flower, Dementia is a generic name for various forms of cognitive impairment



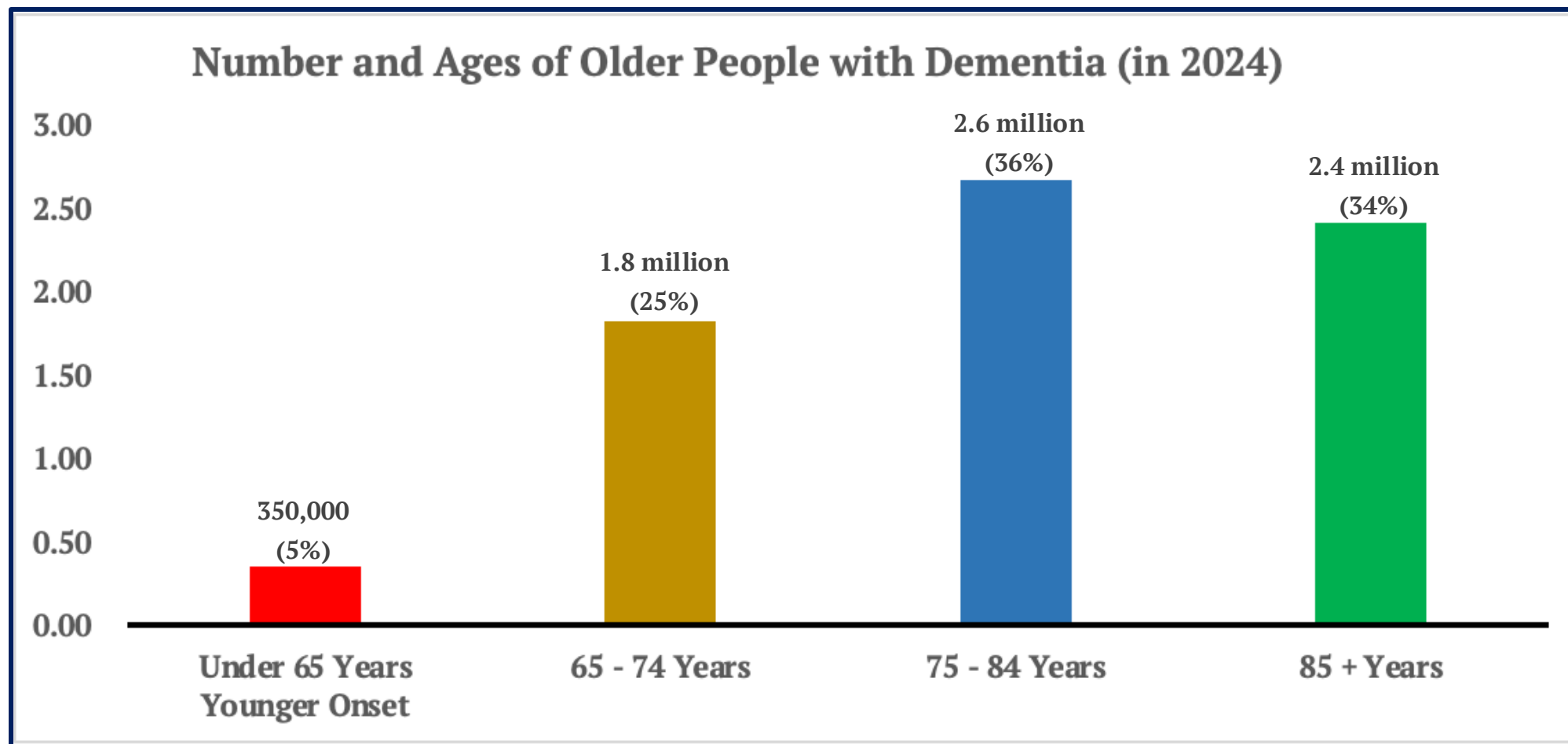
What Is Alzheimer's Disease?

- The most common form of dementia
- Progressive disease with no cure
- It is eventually fatal (named after Alois Alzheimer, a German psychiatrist and neuropathologist, in 1910)

Dementia – Facts and Figures

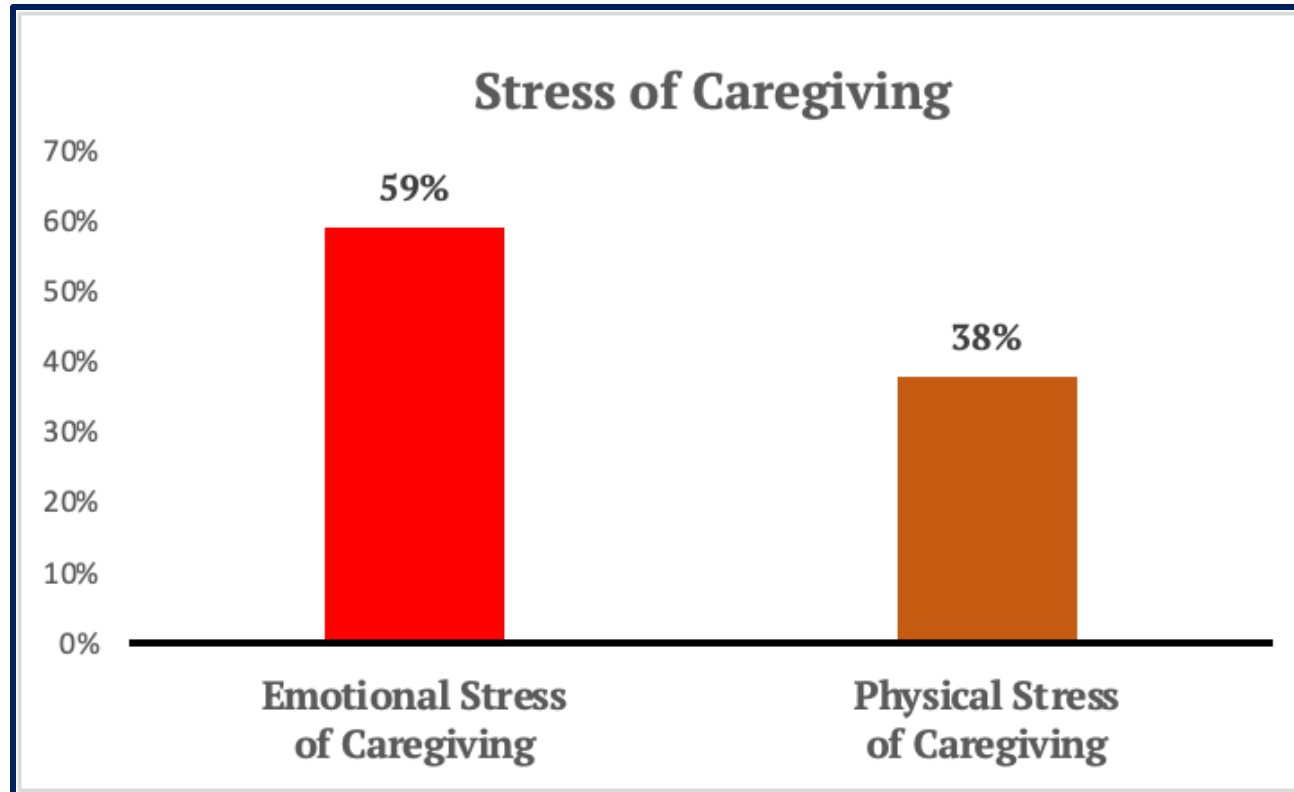
Nearly 7 million Americans Are Living with Dementia (203,000 in Michigan)

One in three seniors dies from Dementia



Dementia – Facts and Figures

- 16 million American provide unpaid care for people with dementia



- I am going to review how I have managed the emotional stress of caregiving

Dementia – Cost of Care

| Cost of Care | Greater Detroit Area | | |
|------------------------------|---------------------------------------|-----------|-----------|
| | Hours and Rate | Per Month | Per Year |
| In-Home Care | | | |
| Home Health Aide | 44 hours per week At \$33 per hour | \$6,292 | ~ \$76 K |
| Assisted Living | | | |
| Assisted Living Facility | 24/7 | \$5,940 | ~ \$71 K |
| Nursing Home Facility | | | |
| Semi-Private Room | 24/7 | \$10,788 | ~ \$129 K |
| Private Room | 27/7 | \$13,657 | ~ \$164 K |

Total lifetime cost of care could exceed \$350,000

Thank you my Sherpa's

I must acknowledge the people who care deeply for me and Sumi
They provide one-on-one, person-centered care at home
Without their professional care and love, Sumi's Journey would be much different



Peggy
2018 – 2022
4 $\frac{3}{4}$ years



Lizzy
2022 to date
3 years



Selina
2019 to date
6 years



Anjana Desai
2022 to date
3 years



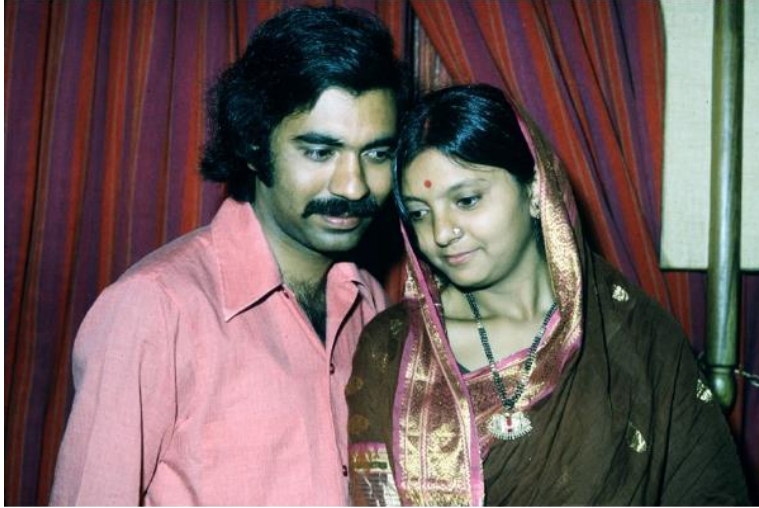
Kailash – My Sister
July – Dec 2018
Apr – Jul 2025

They are my Sherpas



Meet Sumi Mehta

- **In the 1970's**, Sumi was a home maker
Raised two children, a daughter and son. They both live in Los Angeles, CA
- **In the late 1980's**, Sumi assisted in my short-lived restaurant venture
- **In the 1990's**, Sumi worked as a travel agent before the days of internet
- Worked at the Gap store in the Somerset Mall, Troy, Michigan
Then moved to the Gap store in the Village Mall near our home in Rochester Hills, Michigan
She worked in the Children's department
- Sumi stopped working in 2009
- Sumi's age: 71
- **How would I describe Sumi?:** Easy going, easy to please, very few hang-ups, no nagging, always full of infectious smiles!
- Dale Carnegie: 3 Cs - Don't Criticize, Condemn and Complain



A little background on me

- I'm 77 years old (Sumi and I have been married for 51 years)
- **Work History:**
 - Spent 40 years in Michigan's car industry, starting in 1977
 - Worked at Ford in Dearborn for 8 years.
 - Spent 23 years at Chrysler, doing different jobs in Engineering, Management, and International Business. Retired in 2007.
- **After Retirement:**
 - Worked as a Senior Consultant for Tata Technologies for 6 years, helping with an Electric Concept Car called eMO2. Then, consulted with the Michigan Economic Development Corporation (MEDC) to attract foreign investment.
- **Education:**
 - Master's degree in Mechanical Design from the University of California, Berkeley (1971), and a Bachelor's degree in Mechanical Engineering from India (1970).
- **Current Role:**
 - Since 2015, I've been a full-time care partner for Sumi.
- **Advocacy:**
 - I write blogs and speak at events to raise awareness about Alzheimer's disease.
 - I have written a book and created an award-winning documentary



A few cautionary notes before we begin:

- This presentation shares personal insights and experiences regarding Alzheimer's disease, dementia, and memory loss
- My approaches may not necessarily apply to every individual's circumstance
- It does not provide professional services in medical, legal, financial, or other fields
- Consult your own experts before implementing any ideas or suggestions



An Approach to Living - Jay Sheth, a friend

Testimonial in My Journey with Sumi book

When someone is down, I refer them to the My Journey with Sumi website for inspiration. I also share your blog messages with many and explain that **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.

Sometimes, to center myself, I read the online caregiving Bible you have created.



MY JOURNEY WITH SUMI

- In 2013, at age 59, my wife Sumi was diagnosed with younger-onset Alzheimer's disease
- At first, I wanted to change Sumi's behavior, then I realized I needed to change myself
- Eventually, I turned to soul searching and reflection to get us both through the initial years of our journey



- Care partnering is like attempting to scale a challenging mountain.
- In our 12+ years of Journey, I have happened to be at a greater height on the mountain
- I have stumbled many times and have learned a few things from other caregivers who are at even greater heights than I am
- At the same time, I have shared my knowledge with other caregivers who are in the early stages of their journey

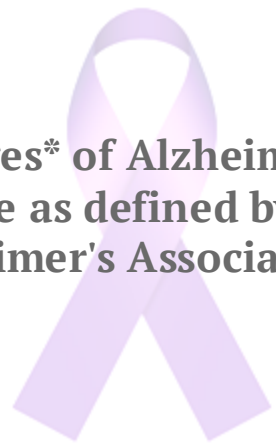
Sumi's Status

Life expectancy of a PWD could vary from 3 -20 years (Age, sex, health, care)

I have chosen 10 years for the 3-Stages. These stages could vary depending on the life expectancy

Pre-Diagnosis Phase

3-Stages* of Alzheimer's Disease as defined by the Alzheimer's Association



Sumi exhibits behaviors highlighted in yellow

0 - 2 Years

2 - 7 Years

7 - 10 Years

Early Stage

Problems with the right word or name

Trouble remembering names when introduced to new people

Challenges in performing tasks

Forgetting material that one has just read

Losing or misplacing a valuable object

trouble with planning or organizing

Middle Stage

Forgetfulness of events or about one's own personal history

Feeling moody or withdrawn

Unable to recall their own address or telephone number

Confusion about the day / where they are

The need for help choosing proper clothing for the season or the occasion

Trouble controlling bladder / bowels

Changes in sleep patterns. Sleeping during the day and becoming restless at night

Increased risk of wandering and getting lost

Personality and behavioral changes. Suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding

Late Stage

Sumi is in the 13th Year of Alzheimer's and is in the Late Stage of her disease

- Not able to communicate her needs discomfort and pain. Super detective read body language, right brain, snoring
- Requires round-the-clock assistance with the activities of daily living (ADLs)
- Lost awareness of recent experiences as well as her surroundings.
- Trouble controlling her bladder and bowel movement (incontinency) Monitoring BM Chart - Free Covid Test
- Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
- Become vulnerable to infections, especially pneumonia

-3

-2

-1

-2010

2011

2012

April 2013

+1

+2

+3

+4

+5

+6

+7

+8

+9

+10

+11

April 2014

April 2015

April 2016

April 2017

April 2018

April 2019

April 2019

April 2021

April 2022

April 2023

May 2024



Agenda

Dementia:

1. What It Is
Facts, Figures and Cost of Care

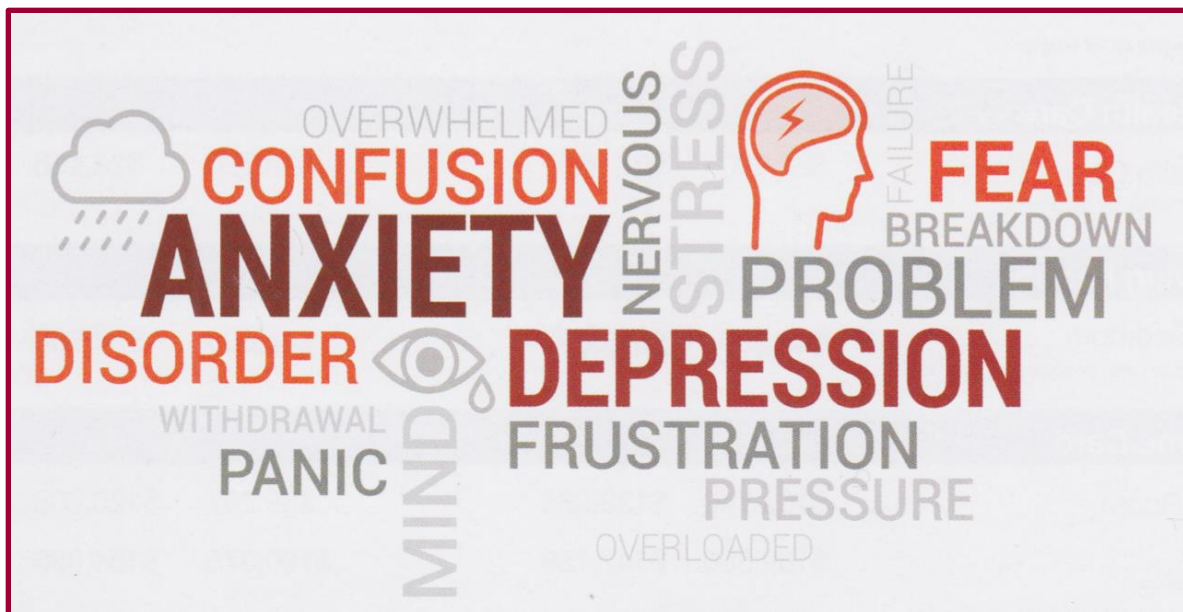
My Journey with Sumi:

2. Introduction
- 3. Emotional Roller Coaster
Mixed Emotions, Grieving Process, and Acceptance**
4. Creative Problem Solving - Sumi's Safety and Well-being
5. Closing Thoughts and Lessons Learned

Emotional Roller Coaster

Sumi's diagnosis evoked a wide range of emotions:

- Confusion, anxiety, fear, frustration, and more – but not depression
- Regrets, guilt and grief have been constant through the Journey



5 STAGES OF GRIEF

by Elisabeth Kubler Ross
Swiss-American Psychiatrist

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance

SARA

- **S**hock
- **A**nger
- **R**eflection
- **A**cceptance

- What?
- Why?
- So What?
- Now What?

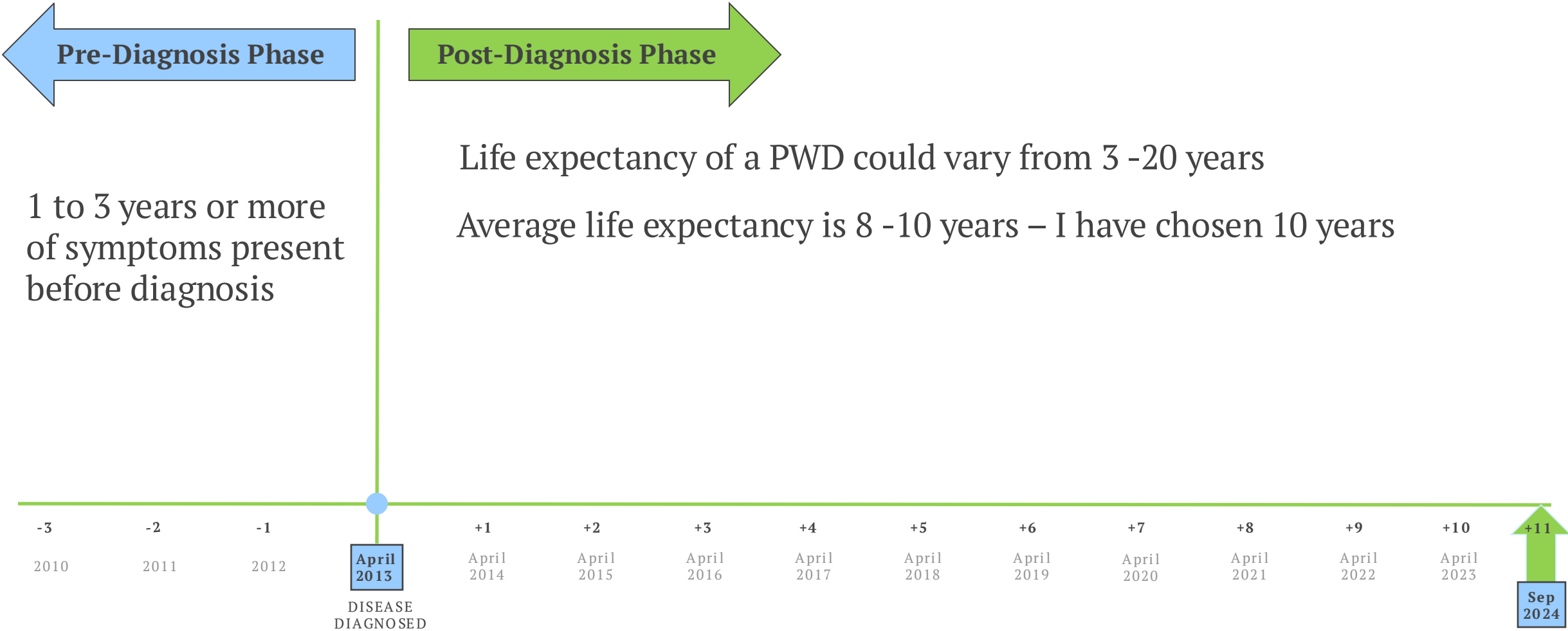
I will share some insights as to
how I've dealt with these emotions

Changing Relationship

- Before Sumi's diagnosis, our relationship was quite reciprocal. We both took care of each other's needs, creating a sense of mutual dependence.
- Household responsibilities were divided according to our individual skills and comfort levels, fostering a harmonious balance.
- However, the onset of the disease brought about a complete reversal. Our relationship became largely one-sided and unequal.
- Loving Sumi became more **intentional** because it wasn't easy during stressful times.
- Honestly, sometimes reflexes took over in tough situations.

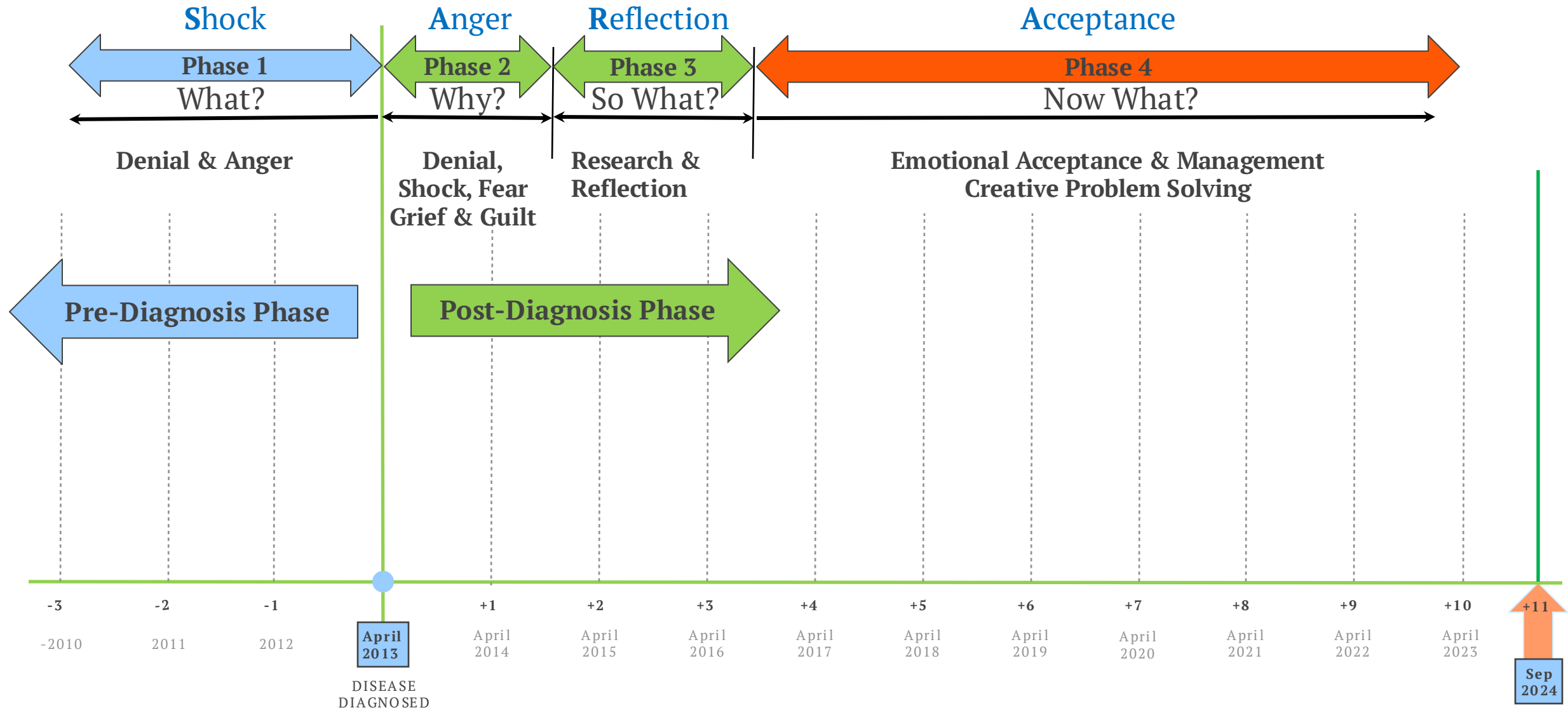


Pre- and Post- Diagnosis Phases

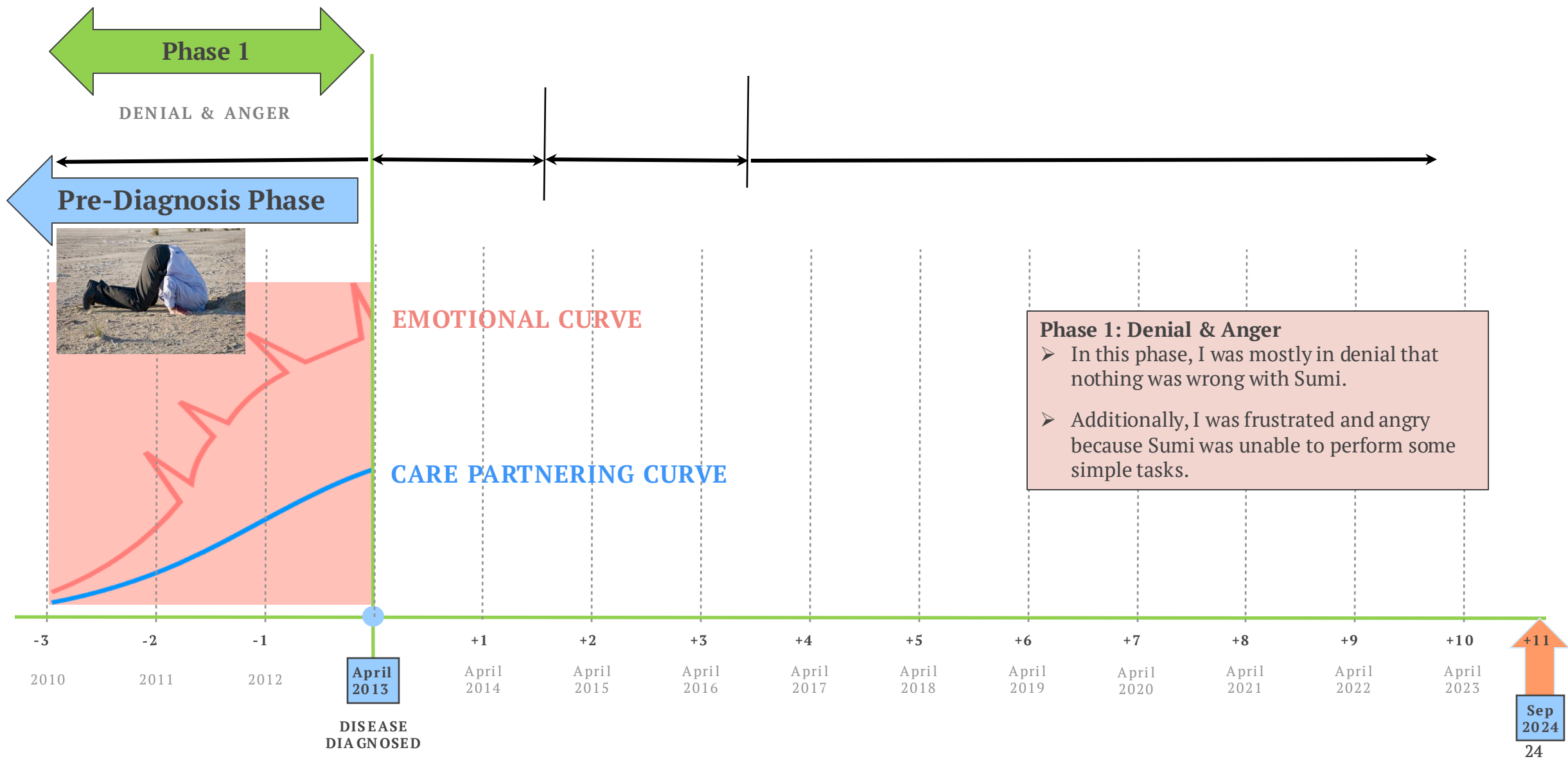


* Source: Alzheimer's Association

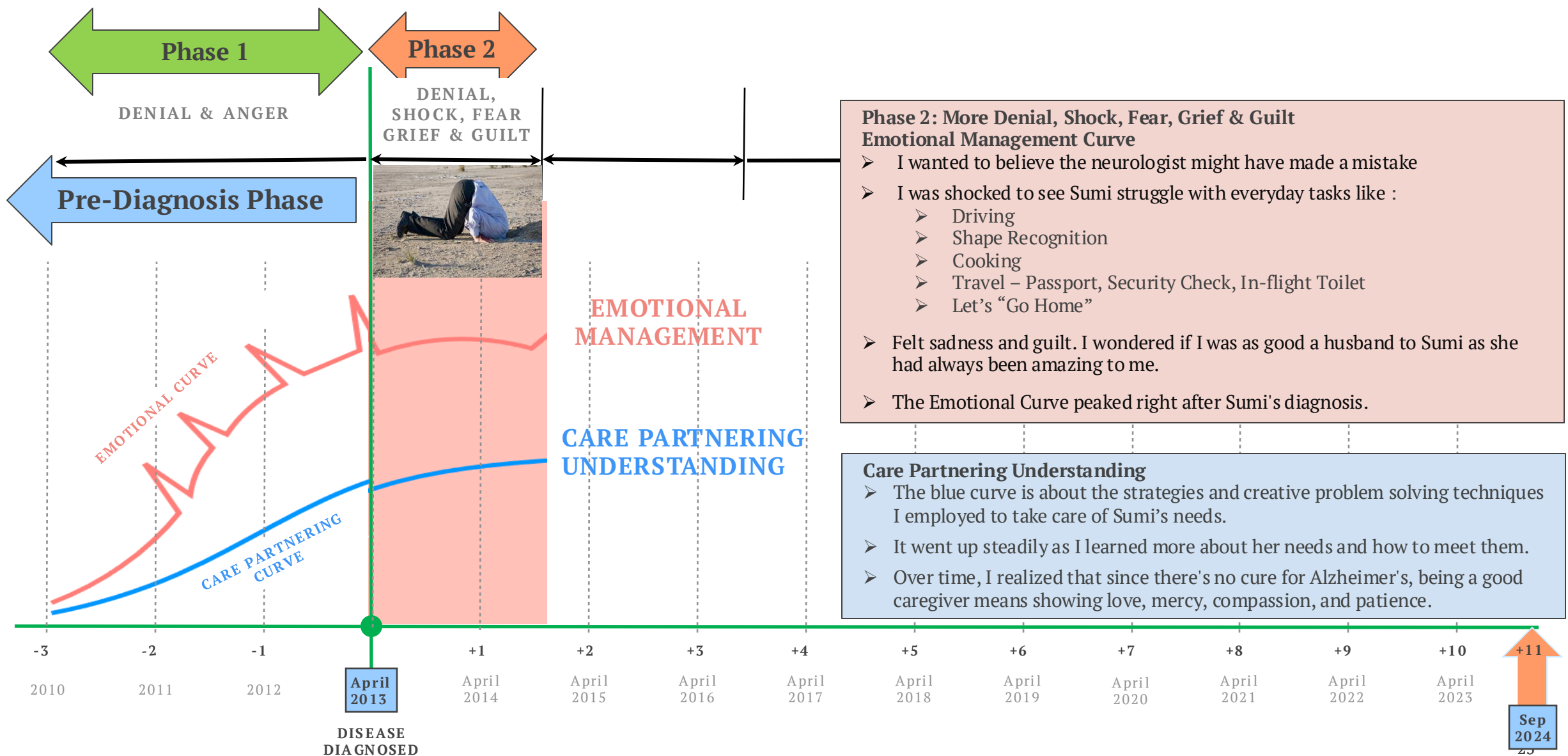
Emotional Curve – Four Phases



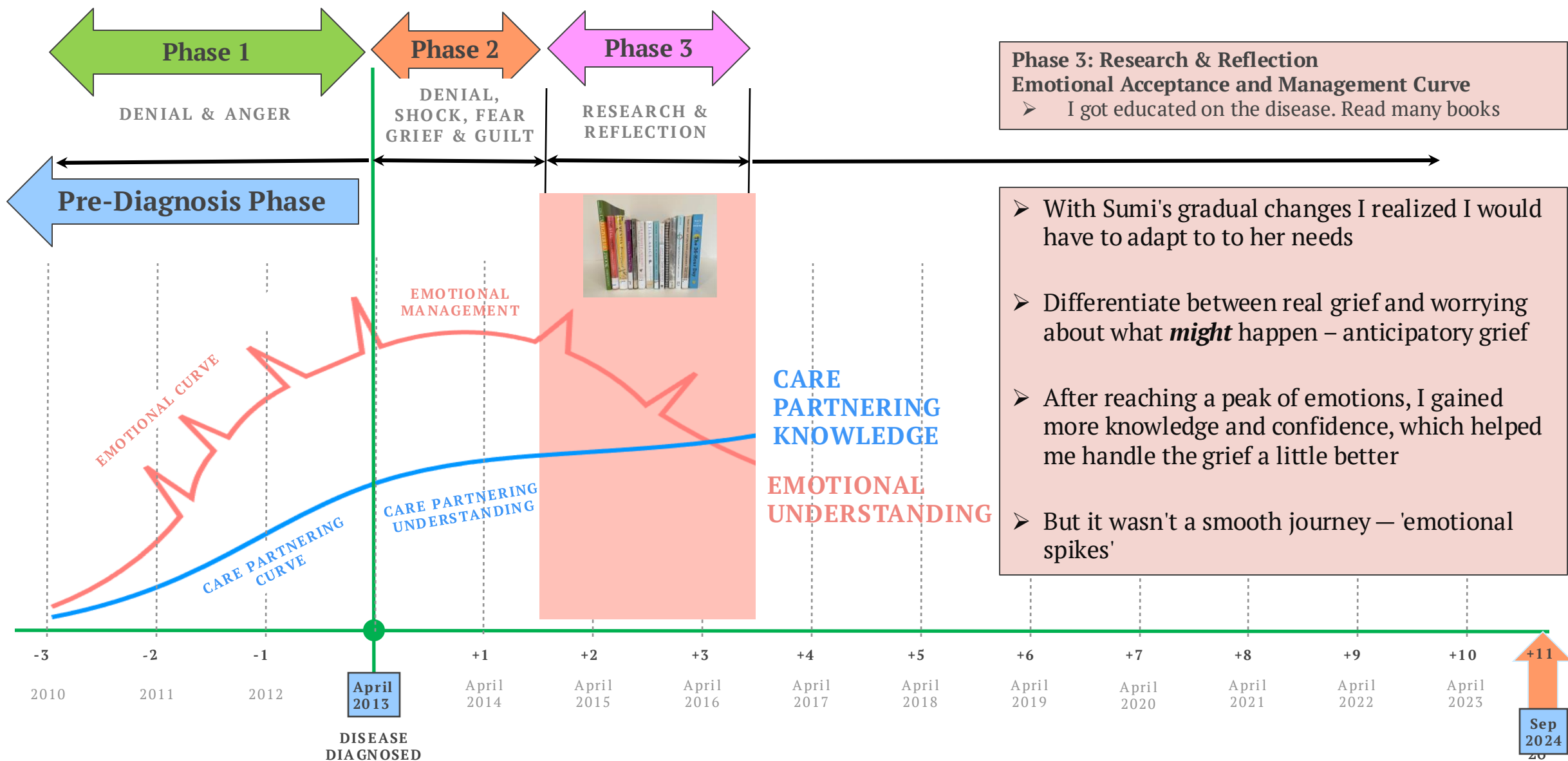
Emotional Curve | Phase 1



Emotional Curve | Phase 2



Emotional Curve | Phase 3



Introspection - (Mental Churning – Distill Into Wisdom and Create the Guiding Principles)



Kabir (1398–1518 CE)

पोथी पढ़ि पढ़ि जग मुआ, पंडित भया न कोय,
ढाई आखर प्रेम काँ, पढ़े सो पंडित होय।

*Pothi Padh Padh Jag Mua, Pandit Bhayo Na Koye
Dhai Aakshar Prem Ke, Jo Padhe so Pandit Hoye*

Translation:

***Reciting scriptures, none became wiser
One who reads the word of Love only becomes wise***

Introspection - (Mental Churning – Distill Into Wisdom and Create the Guiding Principles)



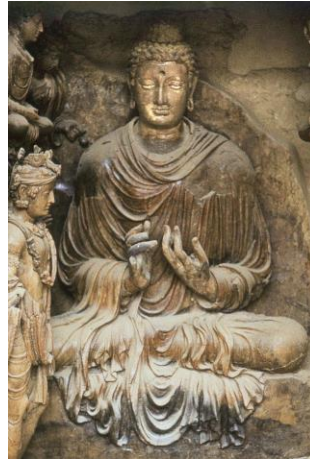
Krishna – Arjuna

The Gita says:

"Do your allotted work (in Sanskrit कर्म) but renounce its fruit
Be detached and work—have no desire for reward and work"

He who gives up action falls; He who gives up only the reward rises

Introspection - (Mental Churning – Distill Into Wisdom and Create the Guiding Principles)



Buddha (500 BCE)

Life is Suffering

Physical, Mental, Emotional, Financial, Relationship (with others and your own self)

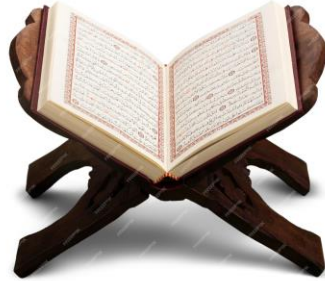
Manage it

Embrace Impermanency- Nature's cycles of creation and destruction

Live in the Present, Mindfulness, Love, Compassion

Then the Life is Blissful

Introspection - (Mental Churning – Distill Into Wisdom and Create the Guiding Principles)



Qur'an 17 Sura Al-Isra, Aya 23

Your Lord decreed that you do good to your parents

If any one of them reaches old age:

- Do not say *Uff* to them (word/expression of anger or contempt)
- Do not scold them
- Address them with respectful words

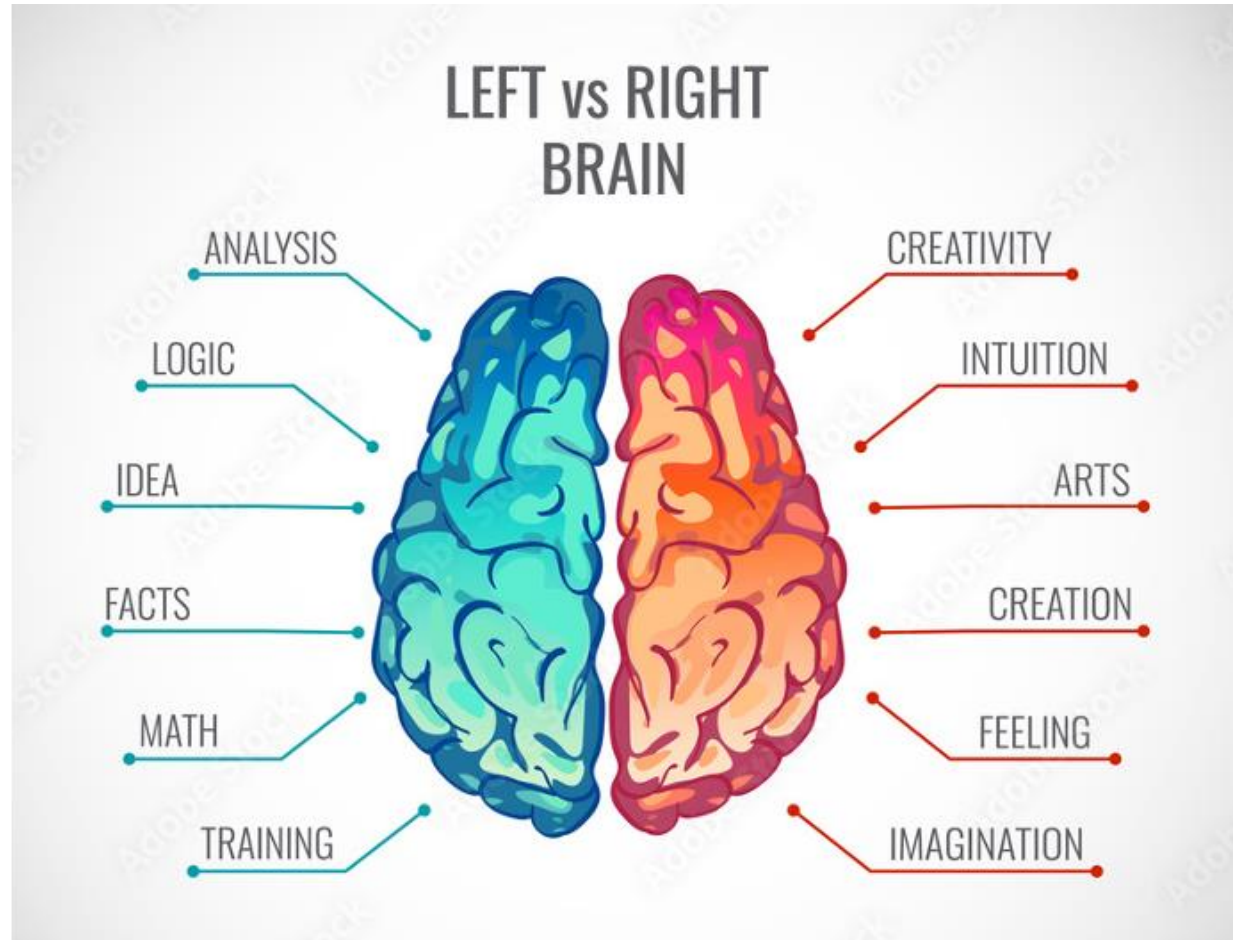
Introspection - (Mental Churning – Distill Into Wisdom and Create the Guiding Principles)



**Love One Another
As I Have Loved You**



Left Brainer



Right Brainer

Alpha Male Tendencies

To

Omega Male Tendencies



Why I Write:

For the first two years after Sumi's diagnosis, I was grieving, brooding, and felt "suffering in silence."

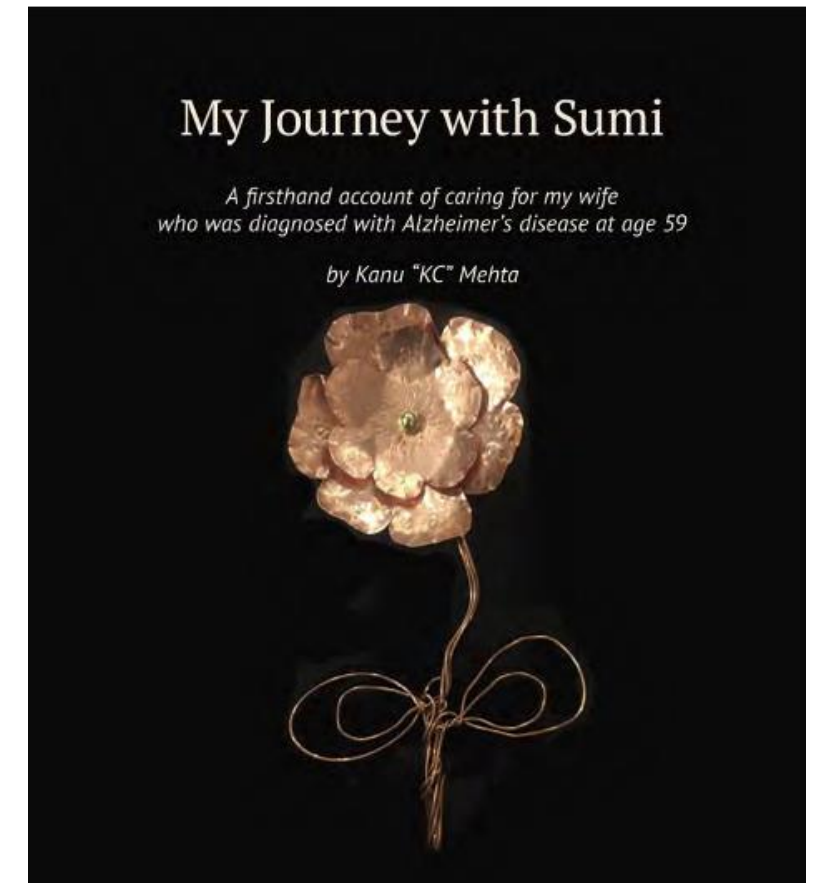
Then I first wrote formally about Sumi's disease in 2015 and continue to write as *My Journey with Sumi* with three main objectives:

1. Increase Awareness of Alzheimer's and fight stigma
2. I write in the moment. Channel and share thoughts and feelings – I find it Therapeutic
3. Let my writing be a barometer of my emotional health

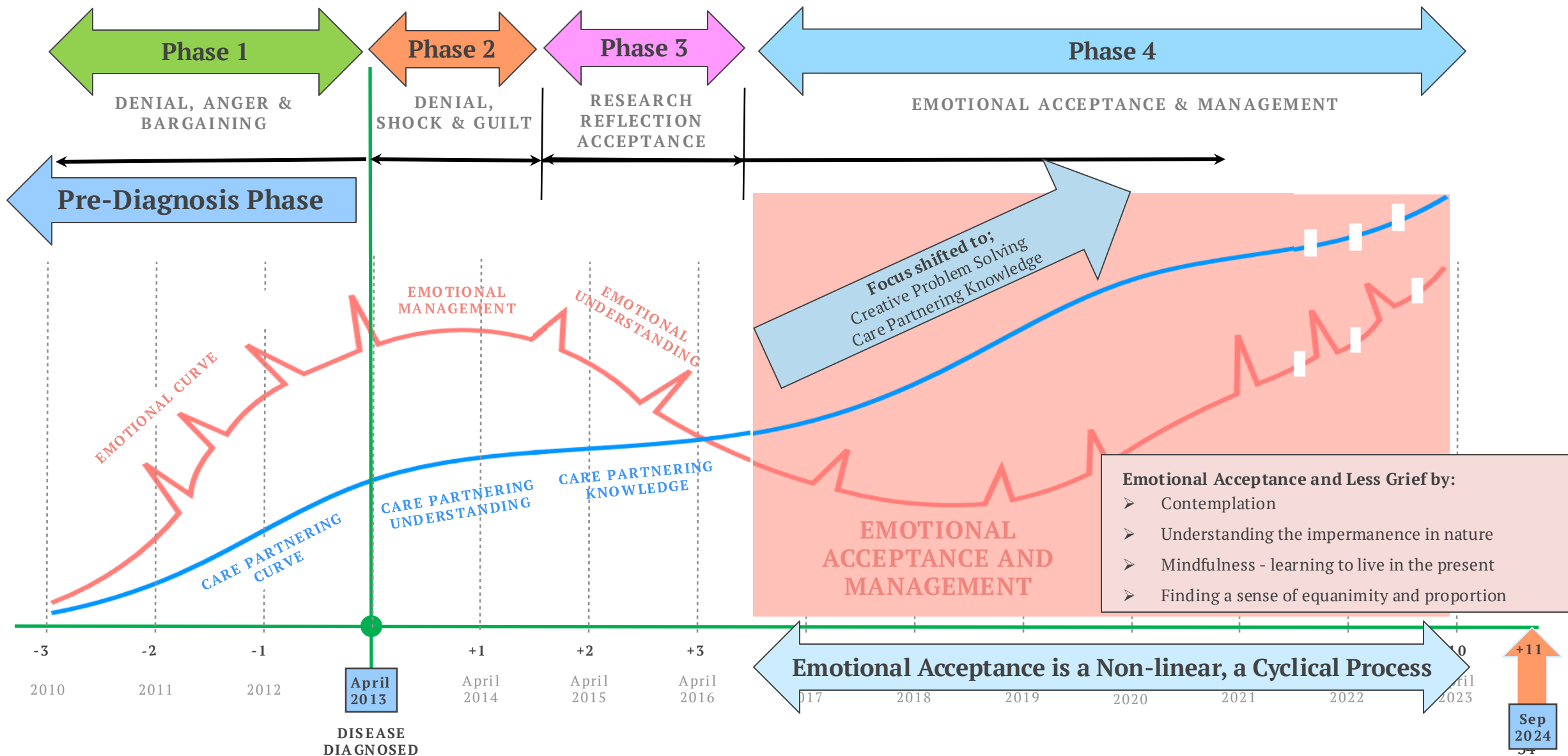
40% of caregivers die before their care recipient

Stanford University Study

All my writing is available in my book and on my website - **My Journey with Sumi**



Emotional Curve | Phase 4

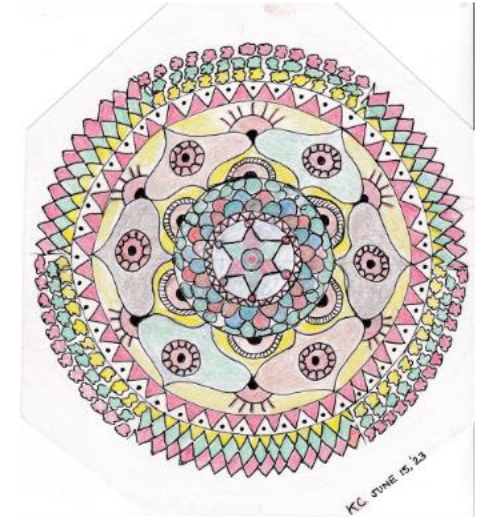


Self Care

I want to emphasize the importance of self-care, which has been a crucial component in leading up to Phase 4 of our journey

- I assembled a caregiving team, including caregivers, doctors, and supportive friends.
- Participated in support groups through the Alzheimer's Association, which has provided valuable support.
- Completed the Powerful Tools for Caregivers Class through AgeWays (formerly AAA-1B).
- Also in CALM, a caregiver's self-care and wellness program offered by THRIVE at Wayne State University in Detroit.
- As I mentioned before, writing and sharing my experiences on my blog has been therapeutic.

- Additionally, since 2018, I have been actively participating in art classes for caregivers offered by the Birmingham Bloomfield Art Center.



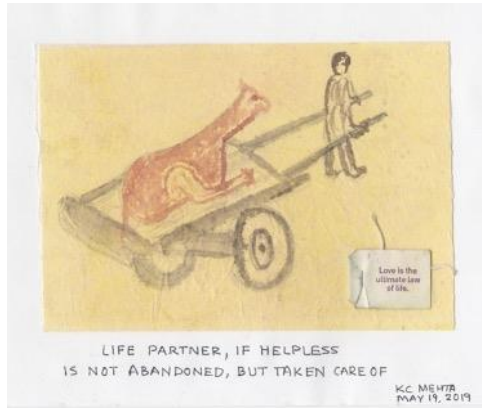
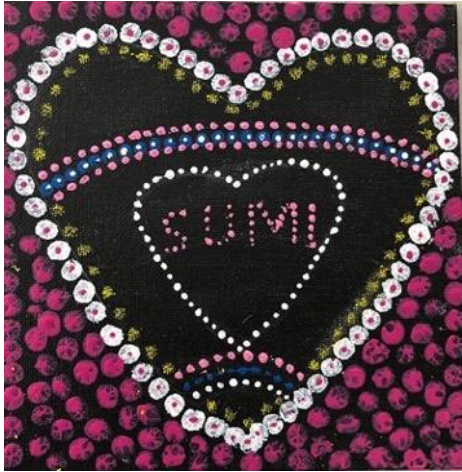
Emotional Curve | Closing Thoughts

- I feel grateful for my good health and financial stability, which allow me to provide Sumi with one-on-one, person-centered care at home.
- Taking care of Sumi has greatly influenced me positively, bringing clarity, focus, and a sense of purpose, which has made me a better husband.

It has helped me find balance and stay focused on what truly matters.

- I've learned to manage my stress more effectively, which has improved my overall health and made me more compassionate and self-reliant.
- The most challenging aspect of caregiving is the sense of isolation. It can make it seem like all dreams and hopes are put on hold. Sometimes, I feel like I am on the edge of a cliff.

However, by pushing forward, I am surprised to have scaled a new height in caregiving. What I thought was a cliff is just another plateau—another new normal.



My Two Sumi's | My Two Worlds



Before Disease - My First Sumi or Sumi *Then*



After Disease- My Second Sumi or Sumi *Now*

As a Care Partner, I grieve for the loss of my Sumi *then*

And I am learning about my new Sumi, as she is *now*

But as the disease progresses, I will also lose this new Sumi

I will grieve for the loss of each Sumi as the years go by, throughout our Journey

My Two Sumi's | My Two Worlds



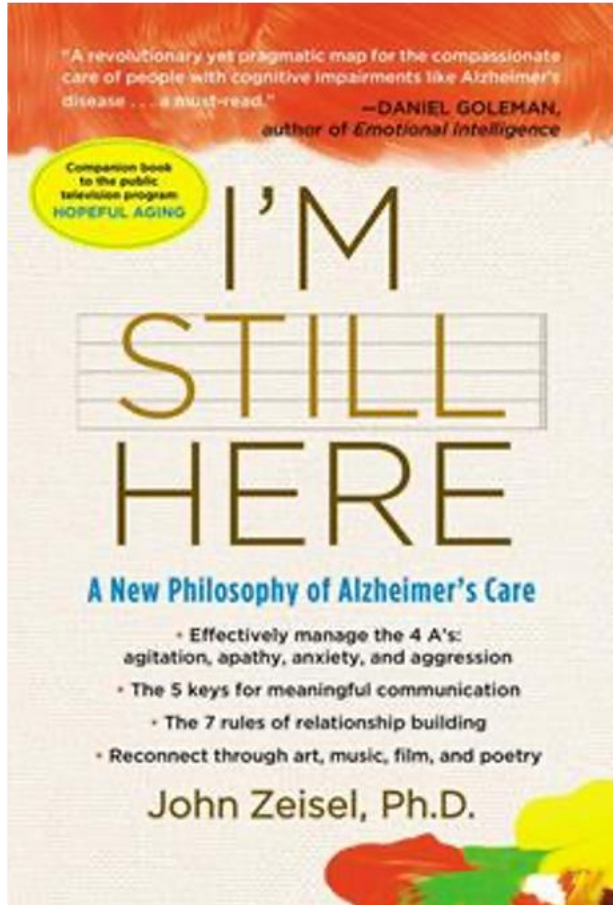
Sumi *Then*



Sumi *Now*

- These two worlds - Sumi then and Sumi now - coexist like two banks of the same river, and it's intensely challenging to live within both simultaneously.
- After the struggle, I've found that I need to navigate between Sumi *then* and Sumi *now* to stay mentally healthy.
- It's like walking on a shaky bridge over a rough river. Trying to remain emotionally stable as I move between my past and present.
- Along the way, I've realized that dealing with grief isn't about forgetting or hiding memories of Sumi. Instead, I recall her on my own terms and in my own time, with less pain.

Creative Problem Solving



What I Learned

Focus on PWD's Strength Keep them connected

Manage their 4 A's – **Agitation, Anxiety, Aggression & Apathy**

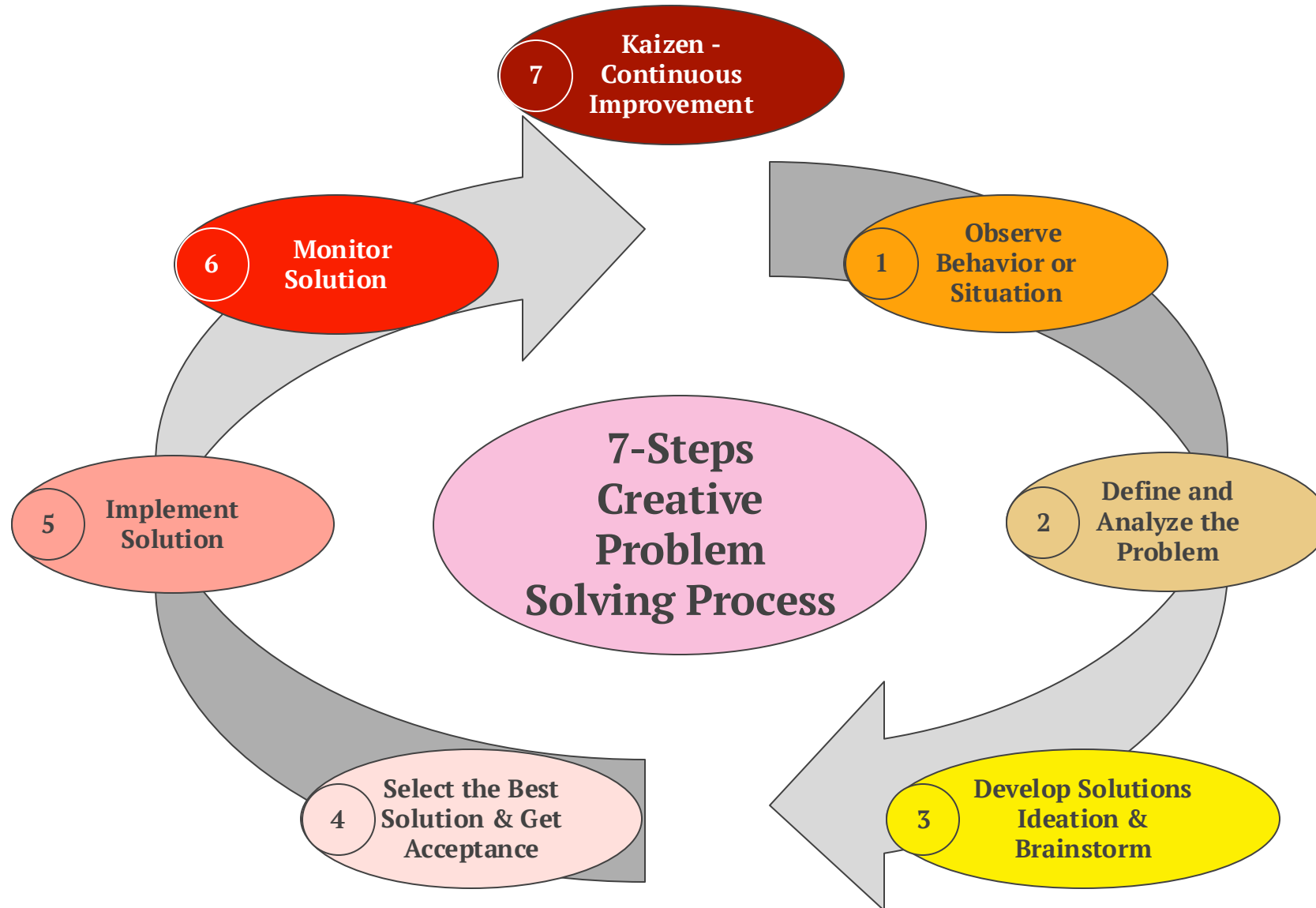
Pharmacological

Non - Pharmacological

Sumi is not on any Medication

Manage Sumi's 4 A's Using the 7-Step Creative Problem Solving Process

Creative Problem Solving



Creative Problem Solving

2017 – Solving Sumi's Agitation



Covered Bathroom Mirror



Covered TV Screen

2020 to Date



Reducing Sumi's Anxiety Communicating with Sumi in Her First Language - Gujarati

Words Spoken by Sumi (2018)

THE WORDS SUMI SAYS

- GAYA (LEFT)
- AYE GAYA (HEY LEFT)
- BADDHA GAYA (EVERYBODY LEFT)
- AVSHE (WILL COME)
- LO (AGREEING TO DO SOMETHING INVOLUNTARILY)
- JO (LOOK)
- HUN JAU (SHOULD I GO?)
- CHALO (LET'S GO)
- HAASH (A SIGN OF RELIEF WHEN COMING TO A COMFORTABLE SITUATION, OR FINISHING AN UNPLEASANT TASK)

Words Spoken to Sumi (2018)

THE WORDS SPOKEN TO SUMI

- SARAS (GOOD, WHEN SUMI DOES WELL)
- SUMI BAHU GAMEY (SUMI IS LIKED A LOT)
- SUMI BAHU SARAS (SUMI IS VERY GOOD)
- SUMI PANI PEE (SUMI DRINK WATER)
- SUMI KHA (SUMI EAT)
- SUMI PAKADE (SUMI HOLD, SPOON TO EAT BY HERSELF)
- DHIRE, DHIRE (SLOWLY - WHEN DRINKING WATER/EATING)
- CHAL CHSEY (IT'S OKAY)
- SUMI CHALO (LET'S GO - FROM ONE POSITION TO OTHER)
- SUMI NE SAAF KARVANU (TO CLEAN SUMI)
- EK, BE (ONE, TWO, PUTTING LEGS IN THE PANTS, OR WHILE CLIMBING/DESCENDING STAIRS)

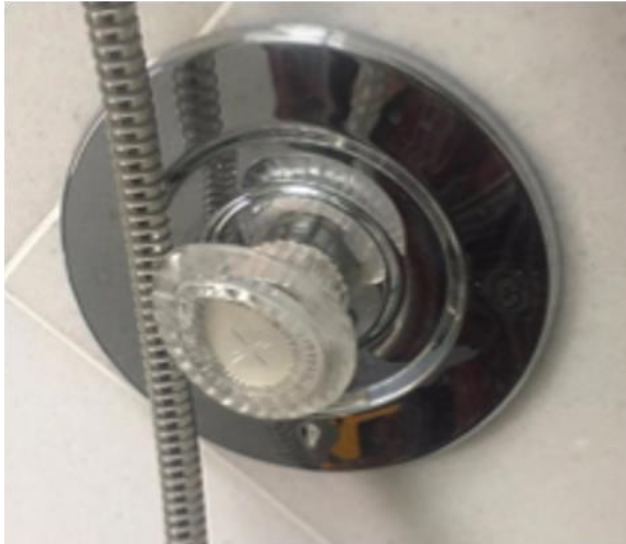
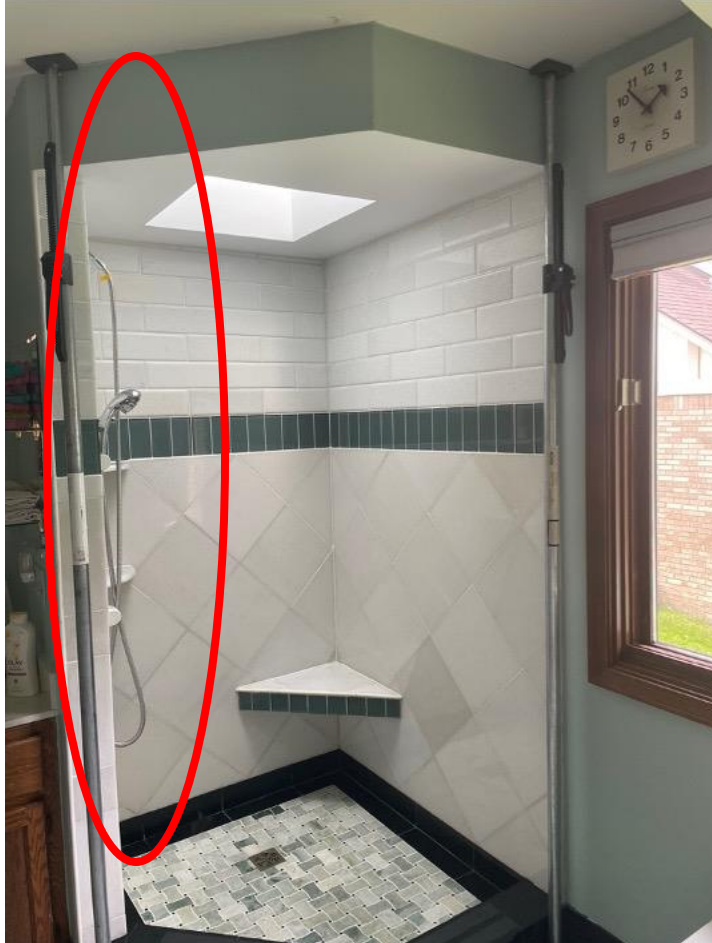
Creative Problem Solving

Language Chart by the Kitchen Table so Caregiver Could Practice the Words



Creative Problem Solving

Sumi's Shower Safety



European Shower Control

\$440



\$6

The Home Depot



\$7

Creative Problem Solving

Ramps



Ramp - Foyer to Sunken Living Room



Garage Ramp

Creative Problem Solving

Vertical Grab Bars @ Shower Stall





Creative Problem Solving - Fall Safety



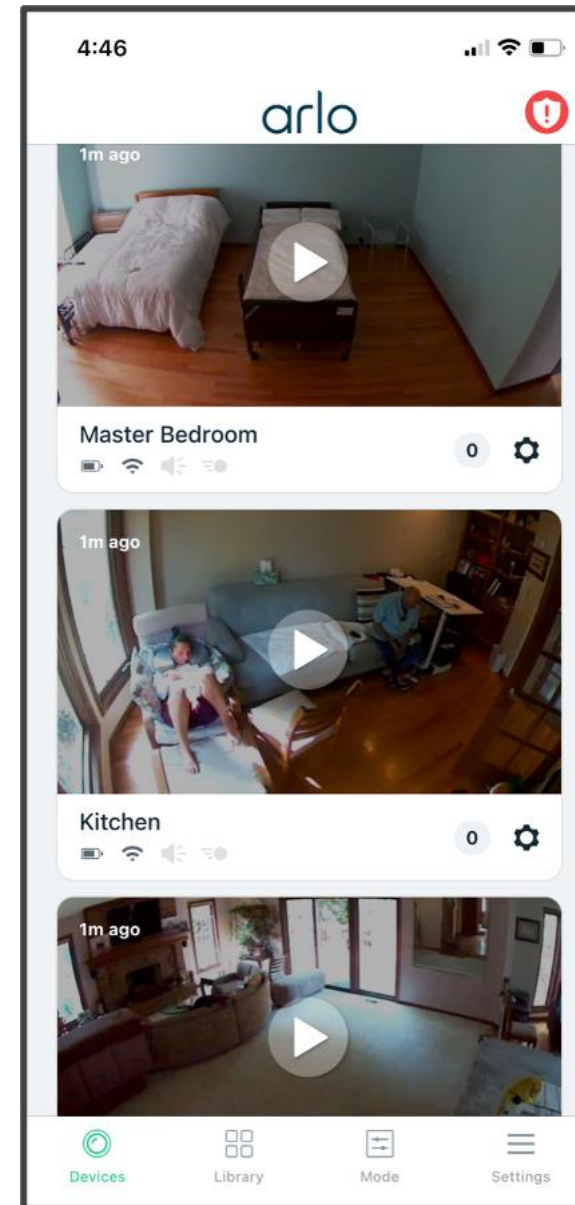
2022 to 2023

Creative Problem Solving

Safety - Monitoring

➤ Installed cameras in the house to monitor Sumi's movements

➤ Installed a motion sensor alarm in the bedroom so when Sumi tries to get out of bed I am alerted to tend to her needs





Closing Thoughts on Creative Problem Solving:

The Only Constant in Life Is Change – Heraclitus (500 BC)

- **I use a 7-step creative problem-solving method at home**, which may also be useful to you as caregivers.
- **No need to reinvent the wheel** if suitable items can be purchased.
- **Pay attention to body language and non-verbal cues**, and recognize signs of distress or unsafe situations that could lead to a dangerous condition.
- **Perfection isn't the goal**; It's about doing what's necessary. Keep what works, discard what doesn't, and stay alert to unexpected issues.
- **Continuous monitoring** and adopting a Kaizen approach for ongoing improvement are essential.



Lessons Learned

What would I tell family caregivers who are new to this journey?



Denial



To Acceptance

- Have all **legal and financial documents in order**: Advanced Directive (Power of Attorney for Healthcare and Do-Not-Resuscitate – DNR), Living Trust, and Will
- **Educating myself about Alzheimer's disease** by reading many books and attending classes and seminars on caregiving has helped me reach a level of emotional acceptance.
- **Join a support group**. The Alzheimer's Association runs support groups for caregivers. I found the support group to be very valuable because I learned about what others are going through, gained a better perspective, and it allowed me to process and channel my emotions.

Lessons Learned

What would I tell family caregivers who are new to this journey?

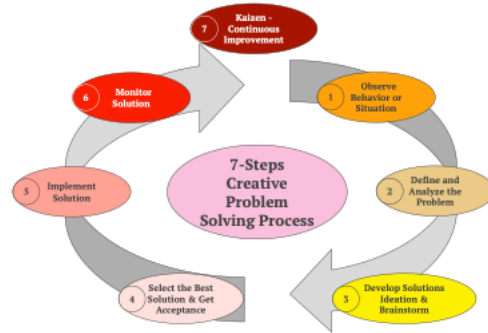
Self Care: Remember it's not being selfish

- **Make time for yourself for self-care.** As they say before a flight takes off, "in case of an emergency, first put the oxygen mask on yourself before helping others."
- **Things that may inhibit self-care:**
 - Guilt for leaving – thinking of putting yourself first
 - Not having reliable caregiver(s)
 - Not wanting to miss a good moment with your loved one
- **Build your own support team. Hire a caregiver.** Reach out for help from family, friends, doctors, and organizations such as the Alzheimer's Association, AgeWays, your local religious center, and others.
- **Make new connections. Engage in new activities**
 - Be an advocate to increase awareness of Alzheimer's
 - Reduce the stigmas and taboos associated with it
 - Created an international award-winning documentary

Lessons Learned

What would I tell family caregivers who are new to this journey?

Creative Problem Solving:



- Problem-solving provides me with a short break from my daily responsibilities
- It serves as a form of self-care
- It gives me small wins

Closing Thoughts

WITH THESE SMALL WINS, I AM ABLE TO KEEP SMILE ON SUMI'S FACE



Sumi, 1974
2 weeks after our marriage



50 years later

Every day I try hard not to let that smile go!



Alzheimer's Poem

By Owen Darnell

Do not ask me to remember.
Don't try to make me understand.
Let me rest and know you are with me.
Kiss my cheek and hold my hand.

I'm confused beyond your concept.
I am sad and sick and lost.
All I know is that I need you.
To be with me at all cost.

Do not lose your patience with me.
Do not scold or curse or cry.
I can't help the way I am acting.
Can't be different 'though I try.

Just remember that I need you,
That the best of me is gone.
Please don't fail to stand beside me,
Love me 'till my life is done.



The Journey Continues.....

Thank you

Q & A