



OUR ALZHEIMER'S JOURNEY – A CAREGIVING LOVE STORY

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

Bloomfield Township Senior Center, Michigan
September 20, 2024
10 am to 11 am



This presentation is on my website – My Journey with Sumi



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



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

The risk factors that can't be changed include:

- Age
- Family history
- Down Syndrome

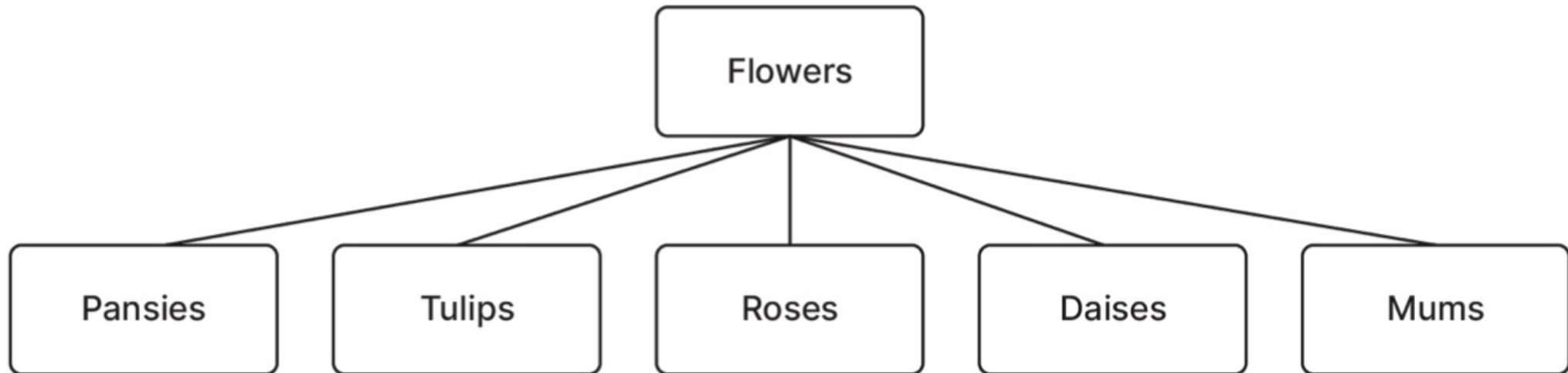
Controllable factors:

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



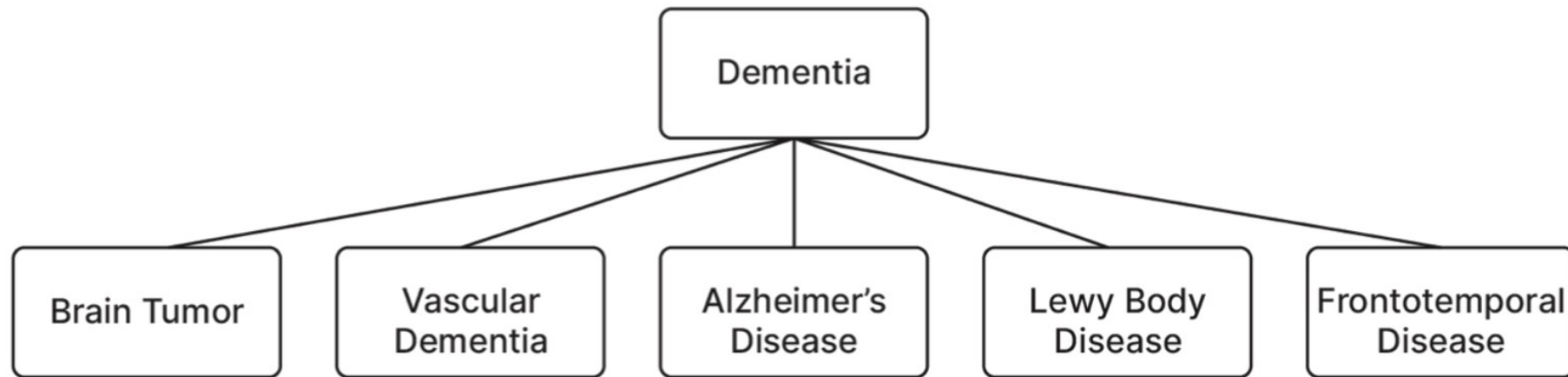
Dementia and Flower Metaphor

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



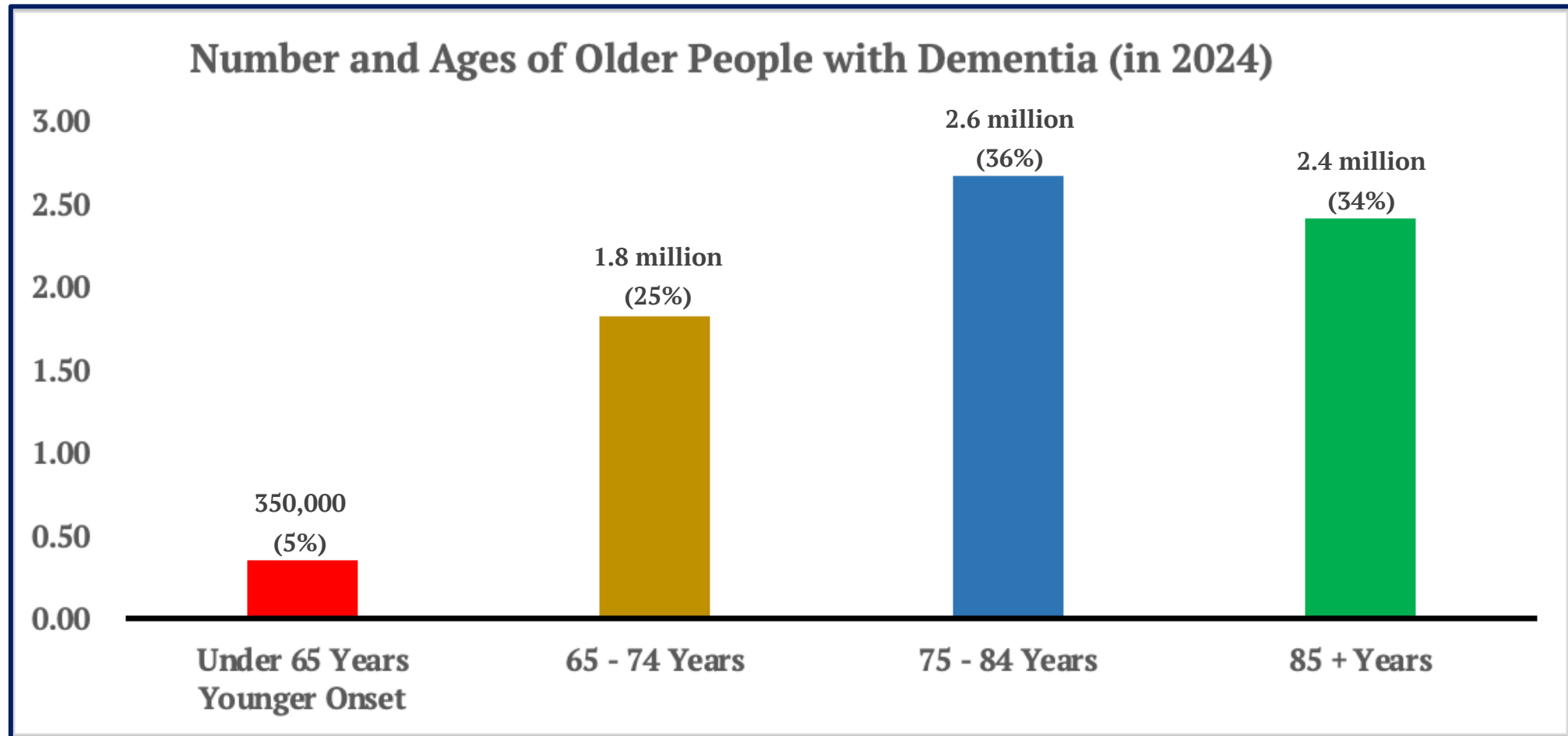
What Is Alzheimer's Disease?

- 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

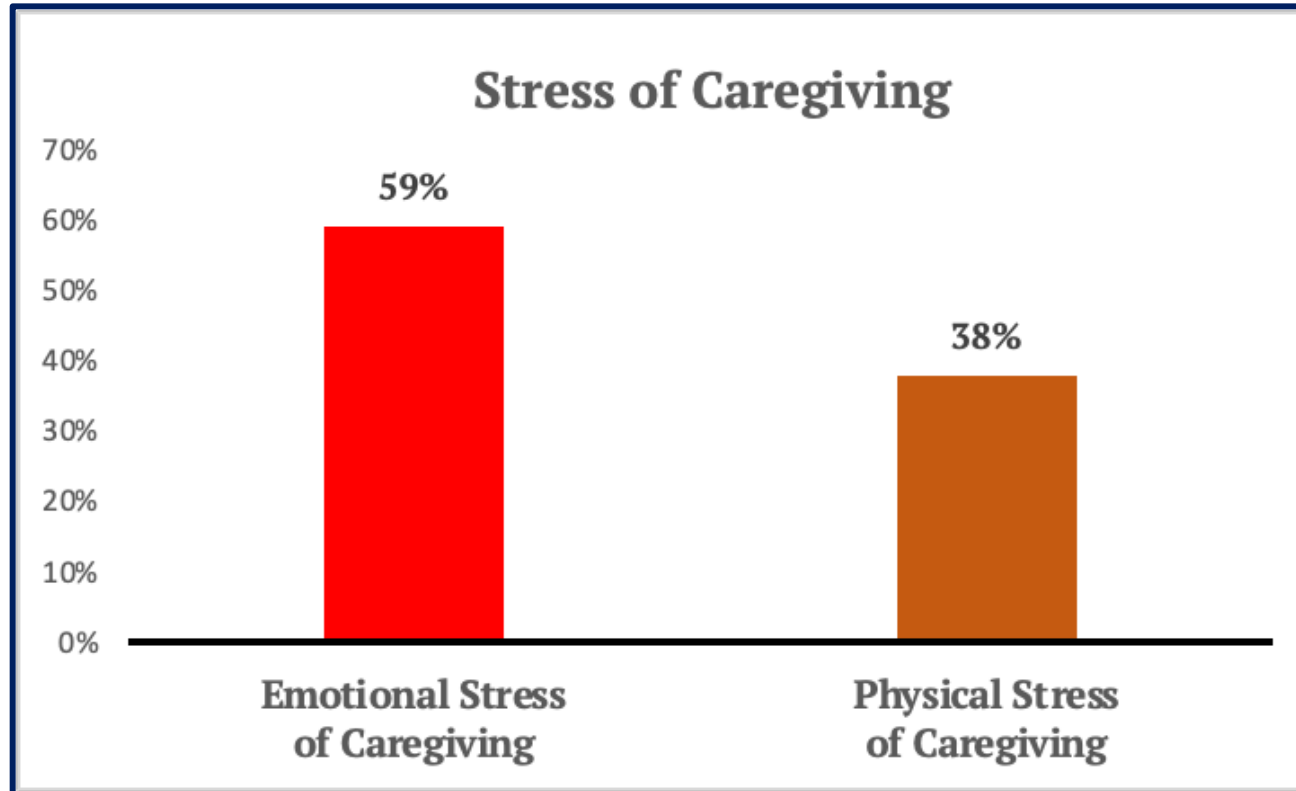
Nearly 7 million Americans Are Living with Dementia (203,000 in Michigan)

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



Cost of Care

	Greater Detroit Area		
	Per Year	Hours and Rate	Per Month
In-Home Care			
Home Health Aide	\$75,504	44 hours per week At \$33 per hour	\$6,292

Assisted Living			
Assisted Living Facility	\$71,280		\$5,940

Nursing Home Facility			
Semi-Private Room	\$129,456		\$10,788
Private Room	\$163,884		\$13,657

US Average	
Per Month	Per Year
\$6,292	\$75,504

\$5,350	\$64,200

\$8,669	\$104,028
\$9,733	\$116,796

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

Thank you my Sherpa's

I must acknowledge the people that care deeply for me and Sumi
By providing one-on-one, person centered care at home



Peggy
2018 – 2022
4 ¾ years



Lizzy
2022 to date
2 years



Selina
2019 – date
5 years



Anjana Desai
2022 to date
2 years



Kailash – My Sister
July – Dec., 2018

Without their professional care and love, Sumi's Journey would be much different

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: 70
- **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 50 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 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 taking care of my wife, Sumi, full-time.
- **Advocacy:**
 - I write blogs and speak at events to raise awareness about Alzheimer's disease.





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 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.

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



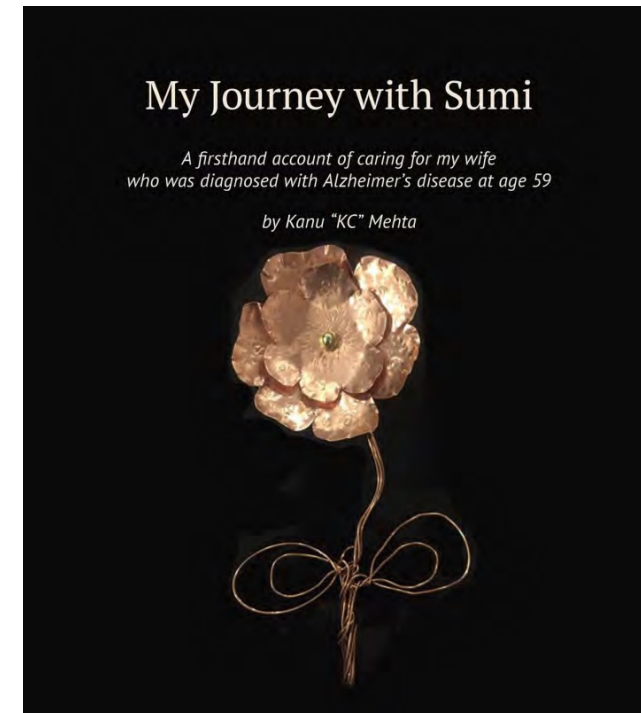
- Care partnering to me is like attempting to scale a challenging mountain. In our 11+ years of Journey, I happen to be at a greater height on the mountain
- I have stumbled many times and have learned few things from other caregivers who are at even greater heights than I am
- At the same time, I have shared my knowledge with other caregivers who are in the early stages of their journey

Why I Write:

- I first wrote formally about Sumi's disease in 2015 and continue to write as *My Journey with Sumi* with 3 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 health

40% of caregivers die before their care recipient
Stanford University Study

- From my writing, I develop stand-alone essays
- Today's presentation is one of my 40+ essays
- All essays are included in my book as well as website - *My Journey with Sumi*



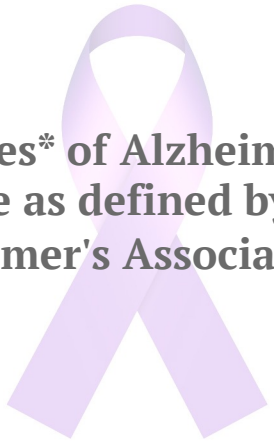
Sumi's Status

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	Middle Stage	Late Stage
<p>Problems with the right word or name</p> <p>Trouble remembering names when introduced to new people</p> <p>Challenges in performing tasks</p> <p>Forgetting material that one has just read</p> <p>Losing or misplacing a valuable object</p> <p>trouble with planning or organizing</p>	<p>Forgetfulness of events or about one's own personal history</p> <p>Feeling moody or withdrawn</p> <p>Unable to recall their own address or telephone number</p> <p>Confusion about the day / where they are</p> <p>The need for help choosing proper clothing for the season or the occasion</p> <p>Trouble controlling bladder / bowels</p> <p>Changes in sleep patterns. Sleeping during the day and becoming restless at night</p> <p>Increased risk of wandering and getting lost</p> <p>Personality and behavioral changes. Suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding</p>	<p>Sumi is in the 12th Year of Alzheimer's and is in the Late Stage of her disease</p> <ul style="list-style-type: none"> ➤ 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. Fit, Walks ➤ 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 April 2013 +1 +2 +3 +4 +5 +6 +7 +8 +9 +10 +11

-2010 2011 2012 April 2013 April 2014 April 2015 April 2016 April 2017 April 2018 April 2019 April 2019 April 2021 April 2022 April 2023

Source: Alzheimer's Association - Michigan

DISEASE DIAGNOSED

May 2024



Agenda

Dementia:

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

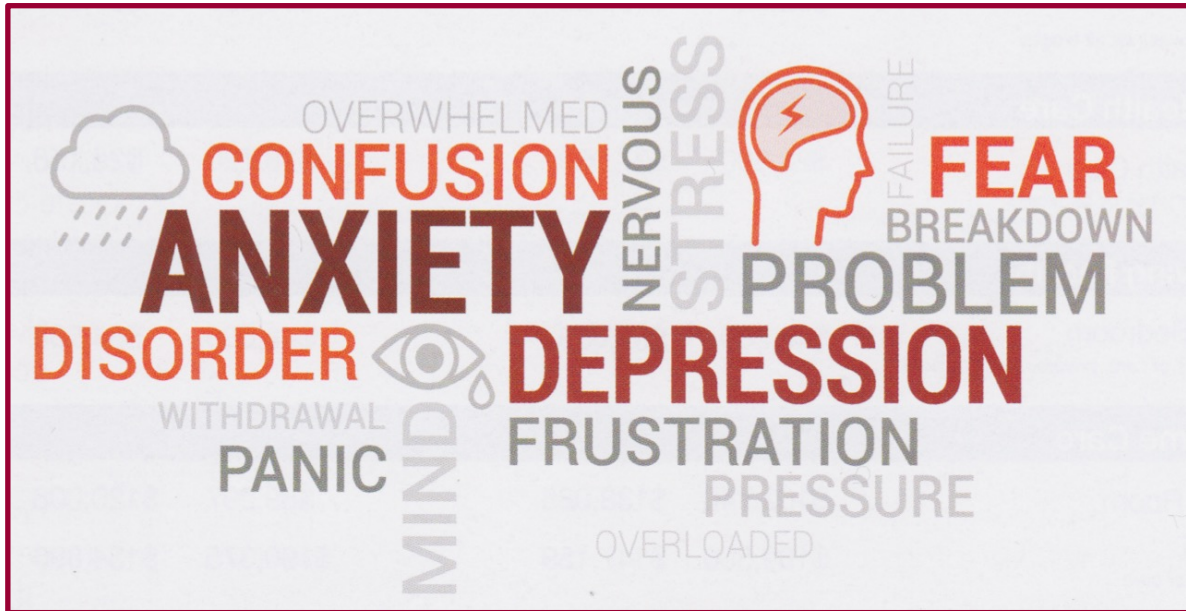
My Journey with Sumi:

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 brought with it a myriad 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?

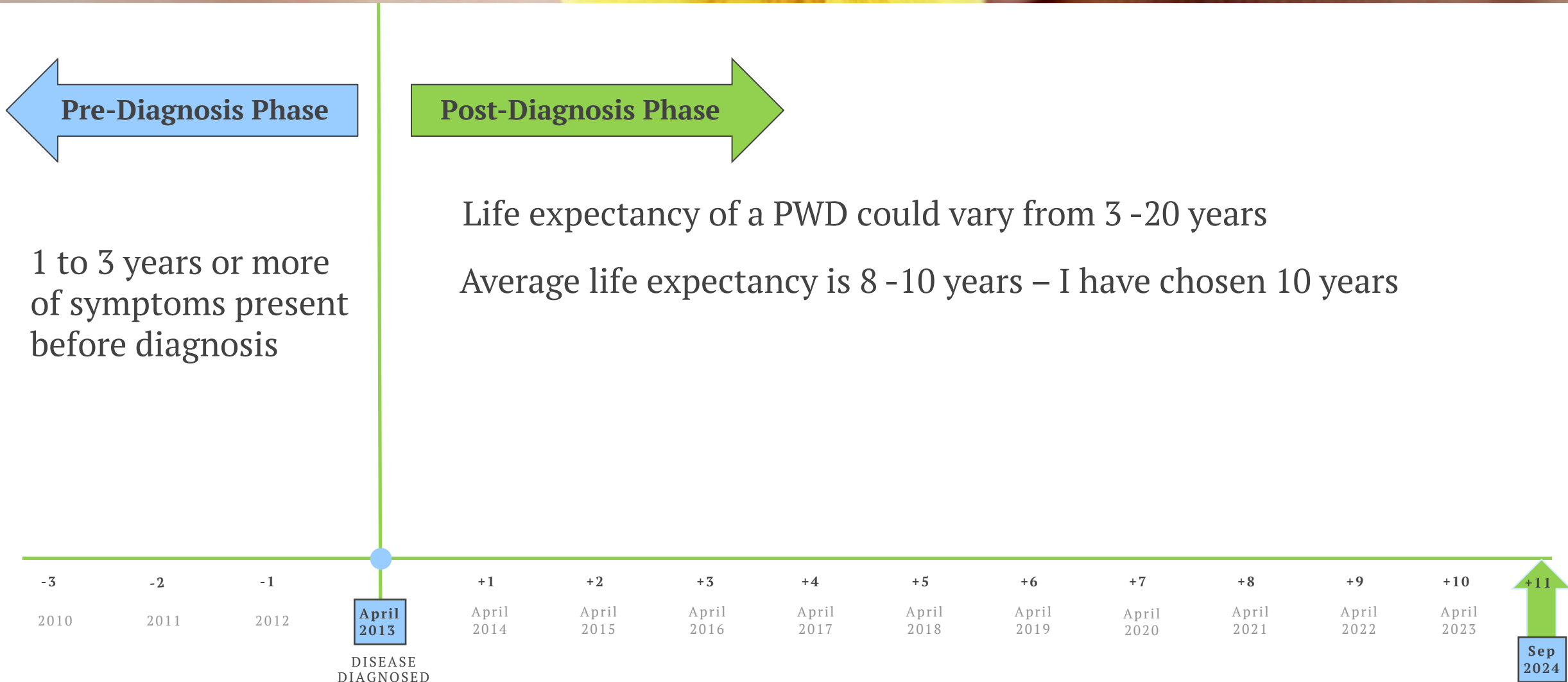
I will share some insights as to how I've dealt with these emotions

Changing Relationship

- Before Sumi's diagnosis, our relationship was quite reciprocal in nature. We both looked after each other's needs, fostering a sense of mutual dependency.
- Household responsibilities were distributed based on our individual skills and comfort levels, creating a harmonious balance.
- However, the onset of the disease brought about a complete reversal. Our relationship became mostly one-sided and unequal.
- Loving Sumi became more intentional as it wasn't always easy to feel it naturally during stressful times. Honestly, sometimes, reflexes took over in tough situations.

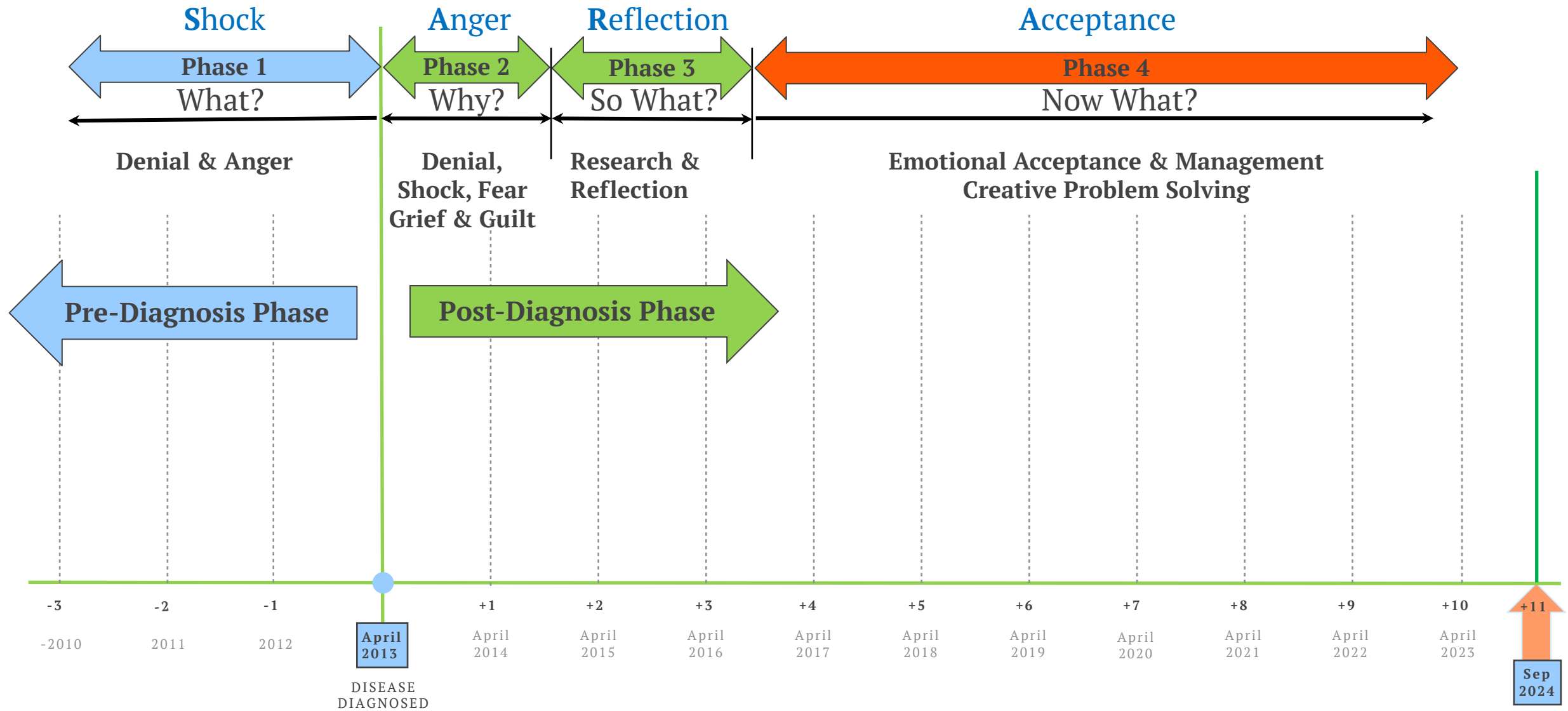


Pre- and Post- Diagnosis Phases

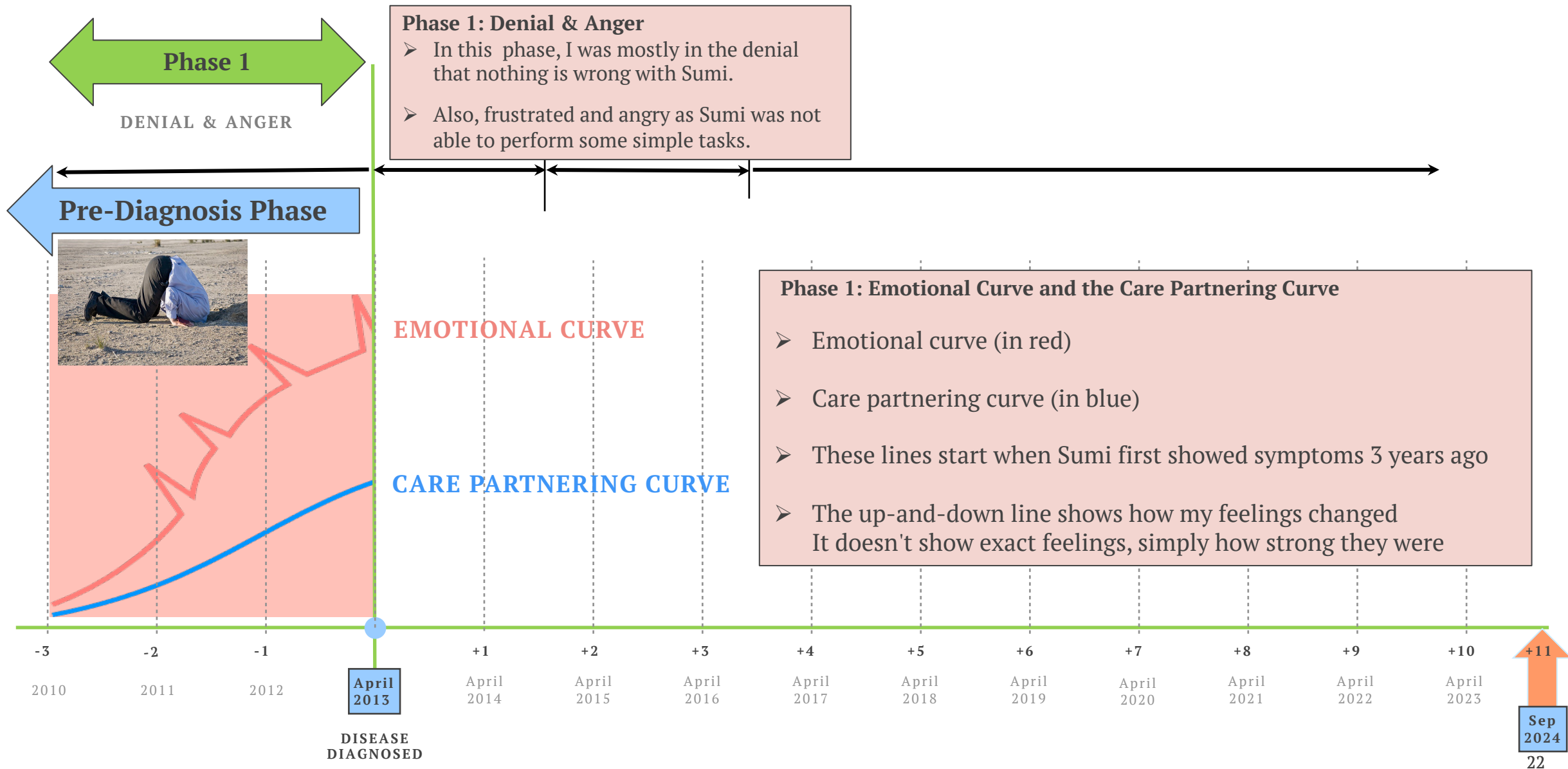


* Source: Alzheimer's Association

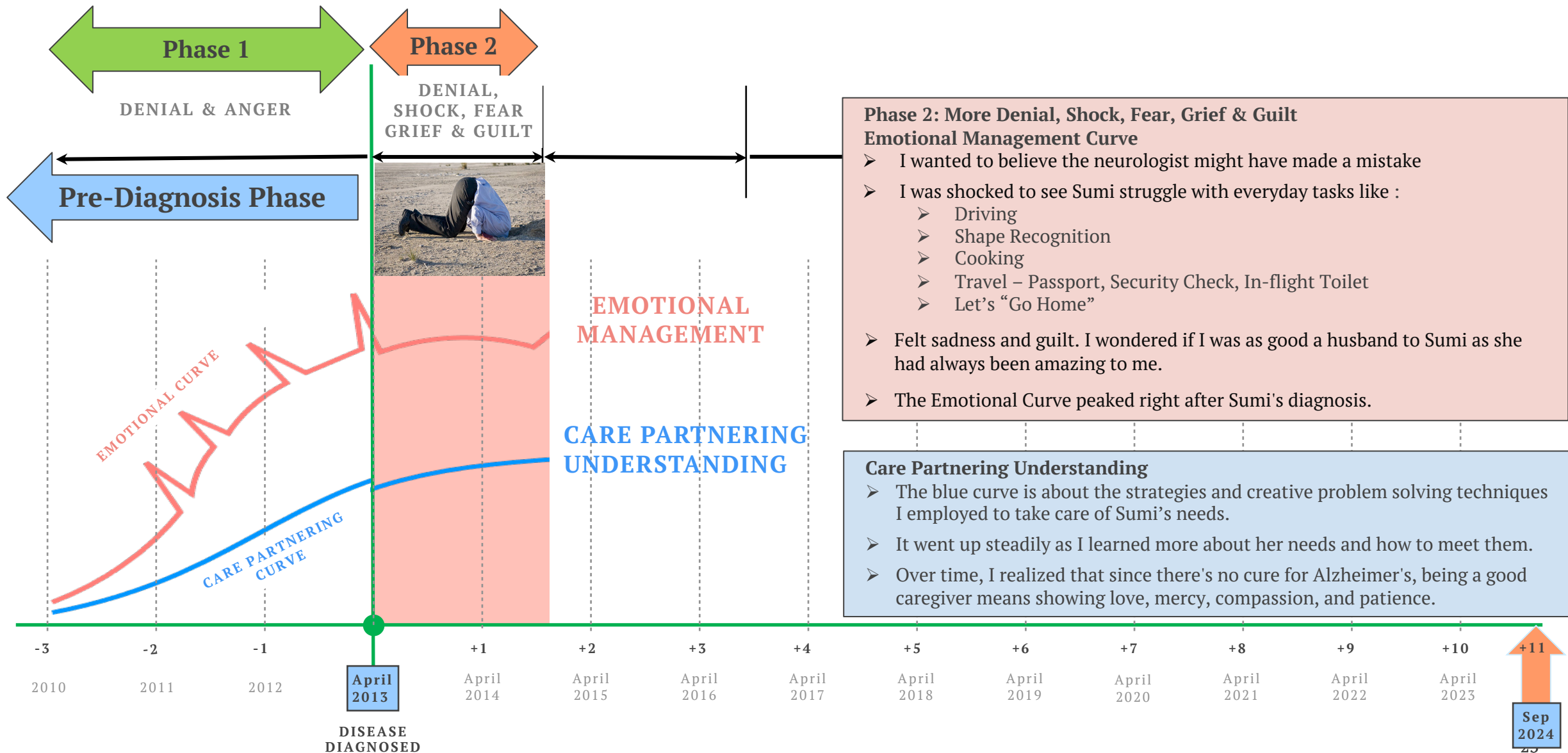
Emotional Curve – Four Phases



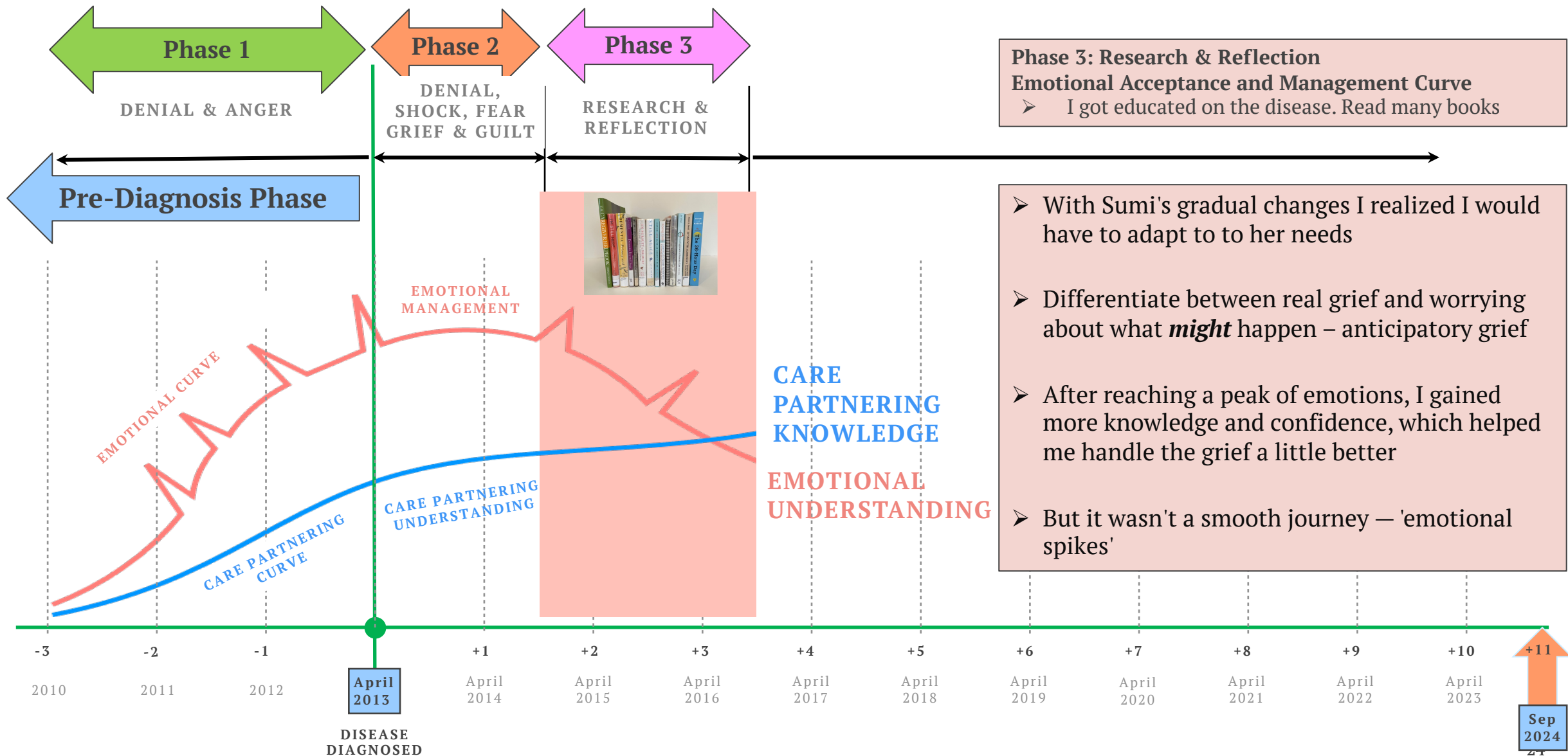
Emotional Curve | Phase 1



Emotional Curve | Phase 2



Emotional Curve | Phase 3



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



Buddha (500 BCE)

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

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

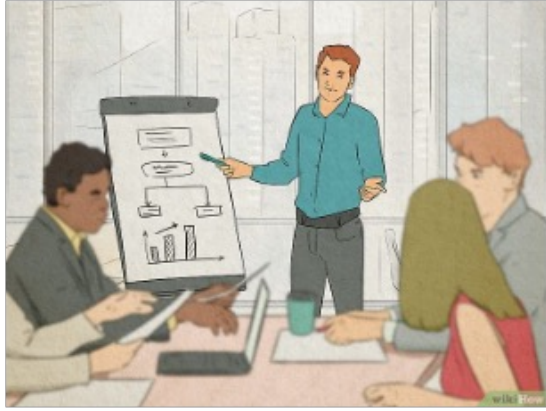
Life is Suffering

Manage it

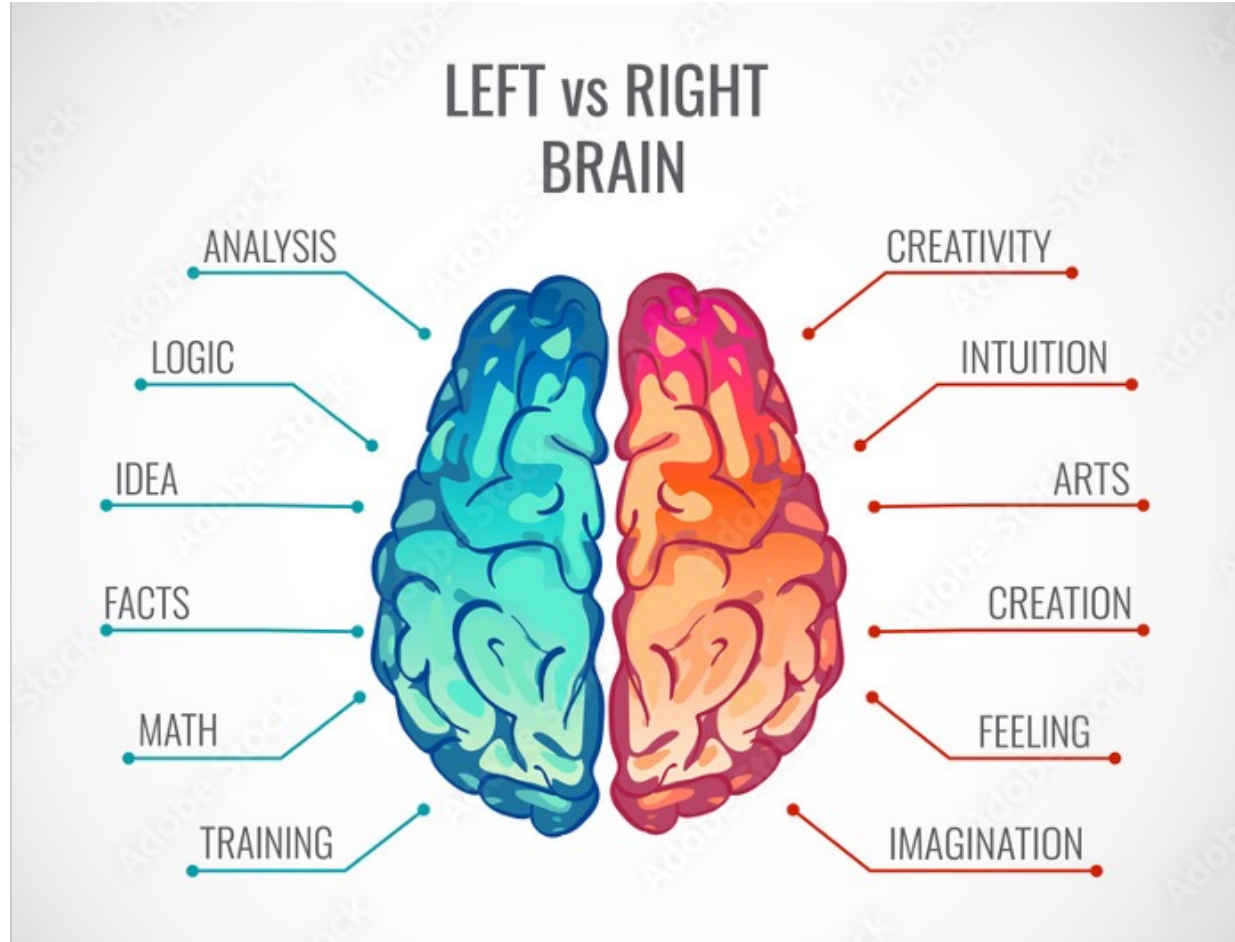
Embrace Impermanency- Nature's cycles of creation and destruction

Live in the Present, Mindfulness, Love, Compassion

Then the Life is Blissful



Left Brainer



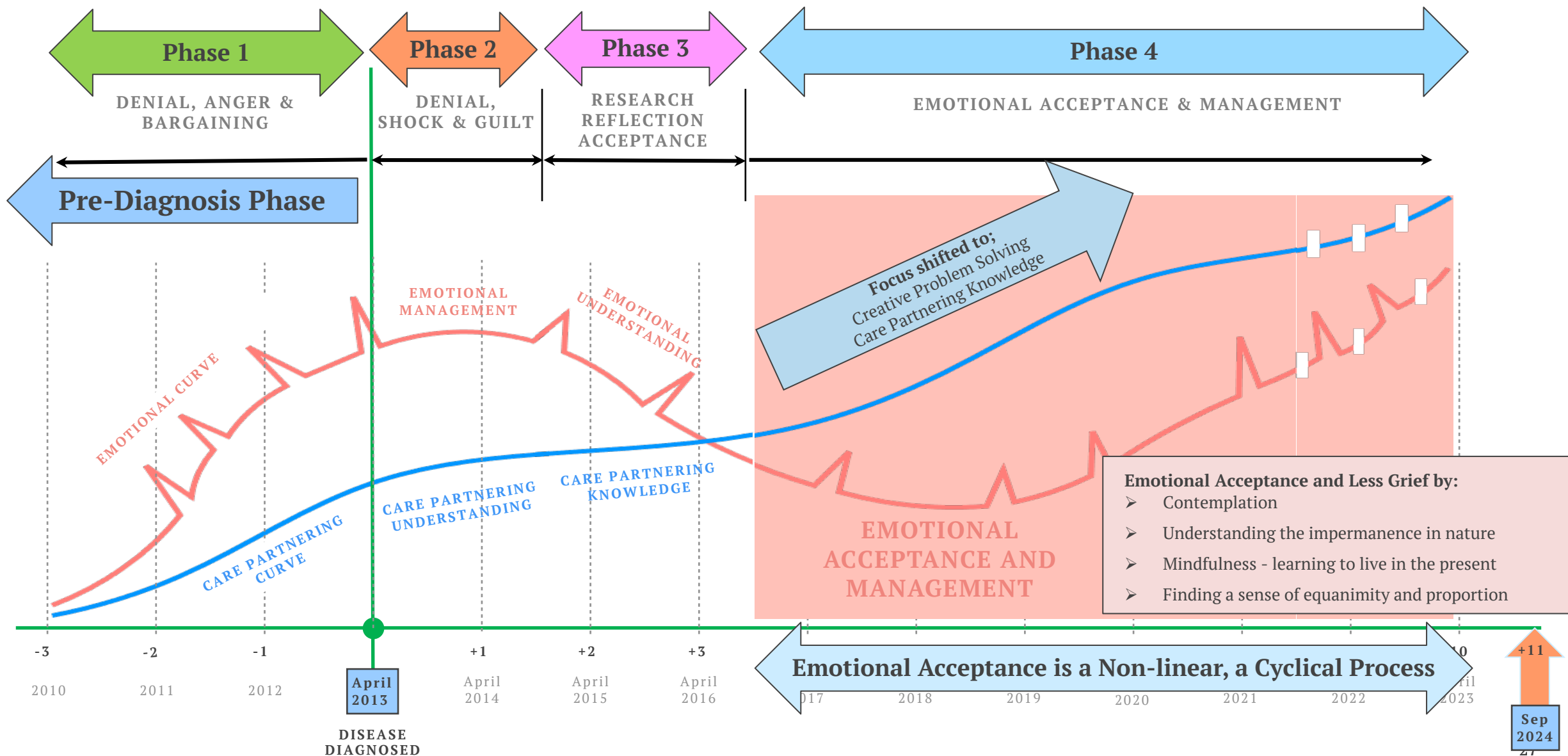
Right Brainer

Alpha Male Tendencies

To

Omega Male Tendencies

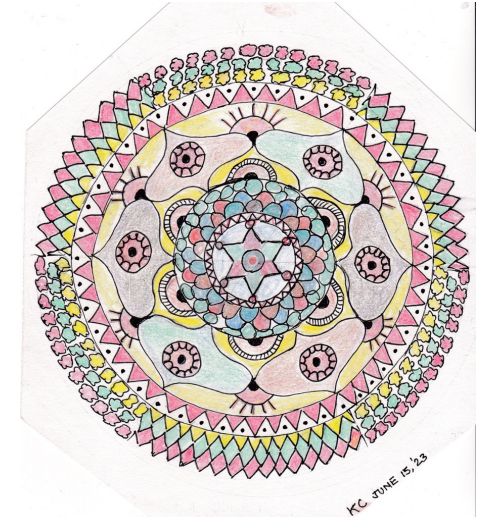
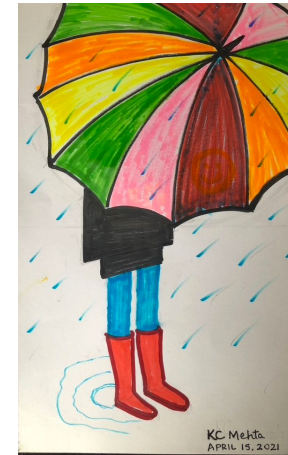
Emotional Curve | Phase 4



Self Care

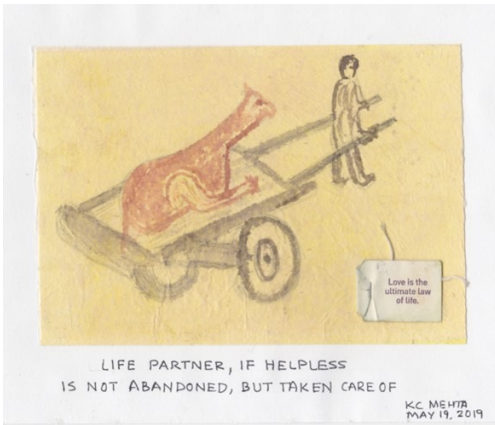
I want to emphasize the importance of self-care, which has been a crucial component in leading up to Phase 4 of our journey

- I established a caregiving team, including caregivers, doctors, and supportive friends
 - Participated in support groups through the Alzheimer's Association which has been a valuable source of support
 - Completed the Powerful Tools for Caregivers Class by 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 previously mentioned, writing and sharing my experiences through my blog have been therapeutic
-
- Additionally, since 2018, I have been actively engaging in art classes for caregivers provided by the Birmingham Bloomfield Art Center



Emotional Curve | Closing Thoughts

- I feel fortunate to enjoy good health and financial stability, which allows me to give Sumi personalized care at home.
- The hardest part of the caregiving is it can feel isolating. It can feel that all dreams and hopes are on pause. Sometimes, I feel as though I am on a cliff's edge. But by pushing forward, 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.
- Taking care of Sumi has changed me in positive ways, giving me a clarity, focus and a sense of and making me a better husband
- It's helped me find balance and stay centered on what truly matters.
- I've learned to manage my stress better, which has improved my own overall health and made me more compassionate and self-reliant.



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



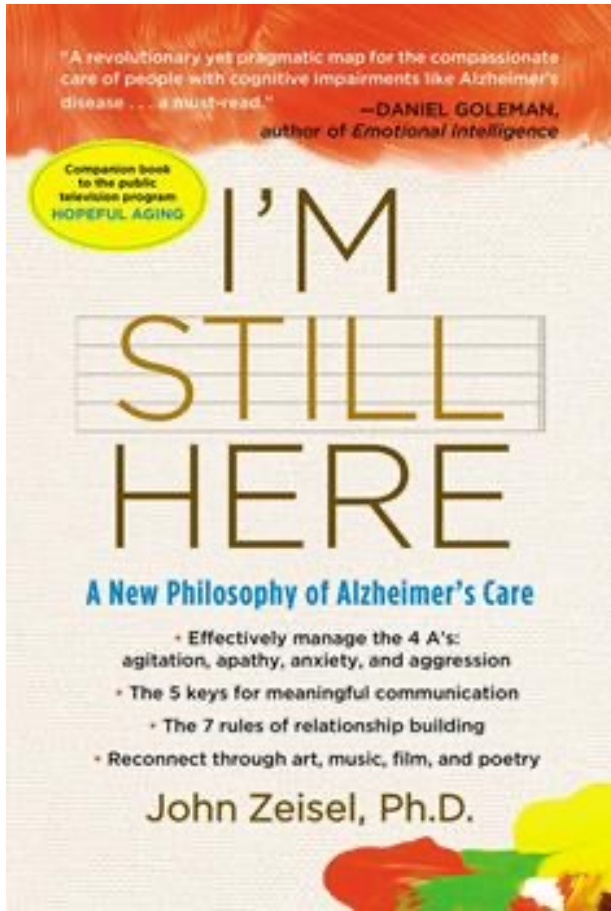
Sumi Then



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**

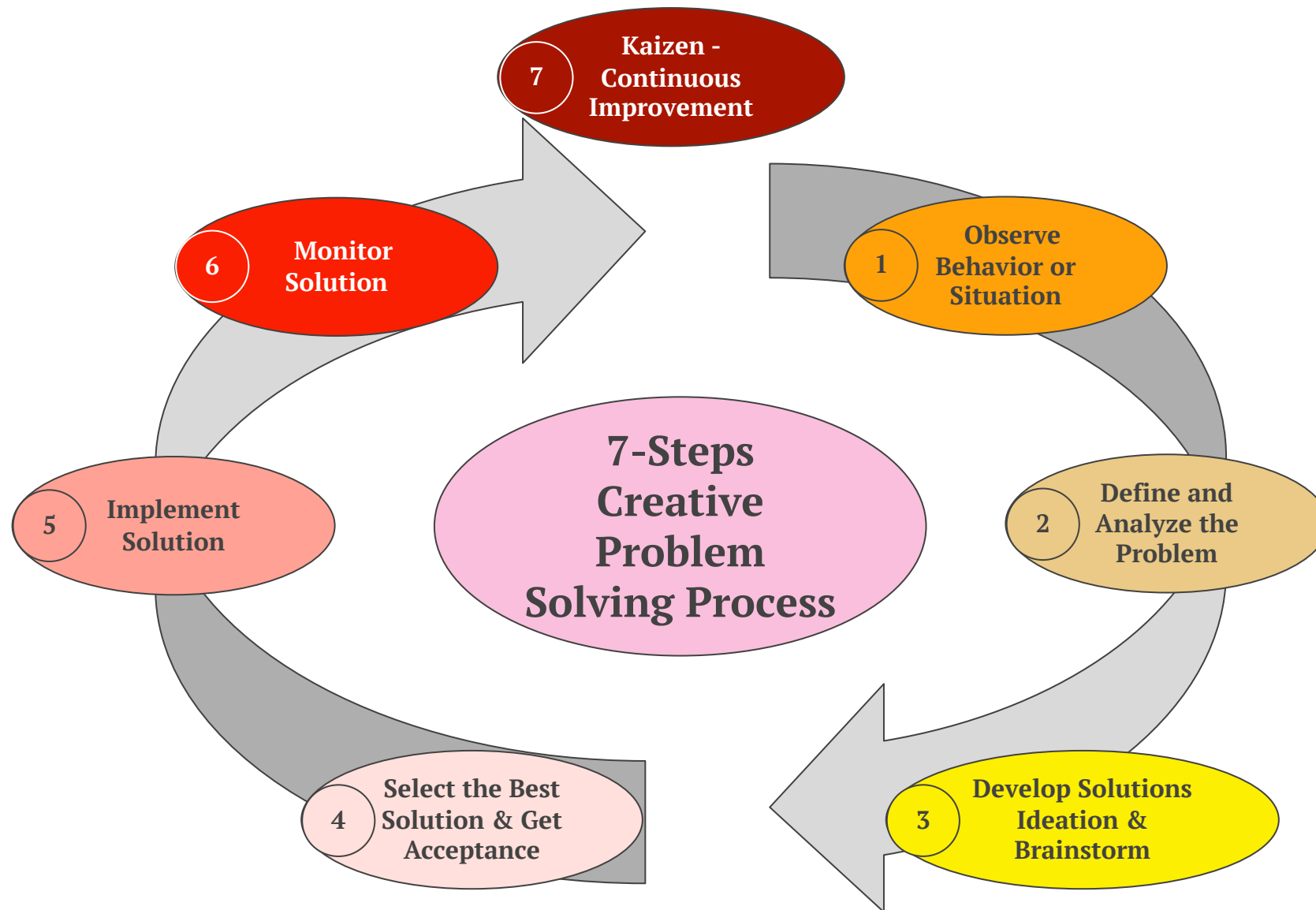
Pharmacological

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

2020 to Date



Covered TV Screen

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



From the Chair



From the Shower



From the Bed

Creative Problem Solving - Fall Safety

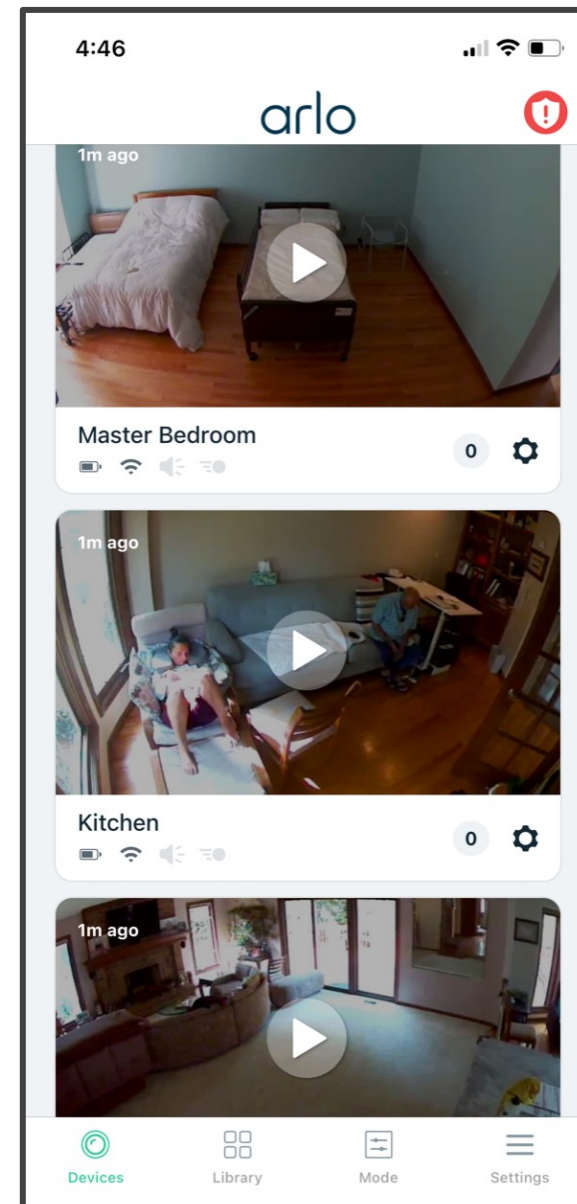


2022 to 2023

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 7-step creative problem-solving techniques at home**, which may also be helpful to you as caregivers.
- **No need to reinvent the wheel** if suitable items could be bought.
- **Observe body language and non-verbal cues**, and identify distress or unsafe situations that could lead to accidents
- **Perfection isn't the goal**; it's about doing what's necessary. Keep what works, discard what doesn't, and stay alert to unforeseen issues.

- **Continuous monitoring** and embracing a Kaizen approach for ongoing improvement are crucial

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
- **Educate yourself about Alzheimer’s disease** by reading many books and attending classes and seminars on caregiving helped me reach a level of emotional acceptance.
- **Join a support group**. Alzheimer’s Association runs support groups for caregivers. I found support group very valuable as I learned about what others are going through, got a better perspective and also helped me process and channel my emotions.

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 from self care:**
 - Guilt for leaving – thinking 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 place and so on.
- **Make new connections. Engage in new activities**

Lessons Learned

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

Creative Problem Solving:



- Developing a proactive problem-solving mindset can improve the safety and well-being of those living with dementia.
- Problem-solving as a caregiver **gives me small victories** and helps serve as a form of self-care, offering a brief break from my daily caregiving responsibilities.

Closing Thoughts

WITH THESE SMALL VICTORIES, 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