Our Alzheimer's Journey

Sumi (my wife, a Person with the Disease – PWD) **and I, as her Care Partner**

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Agenda

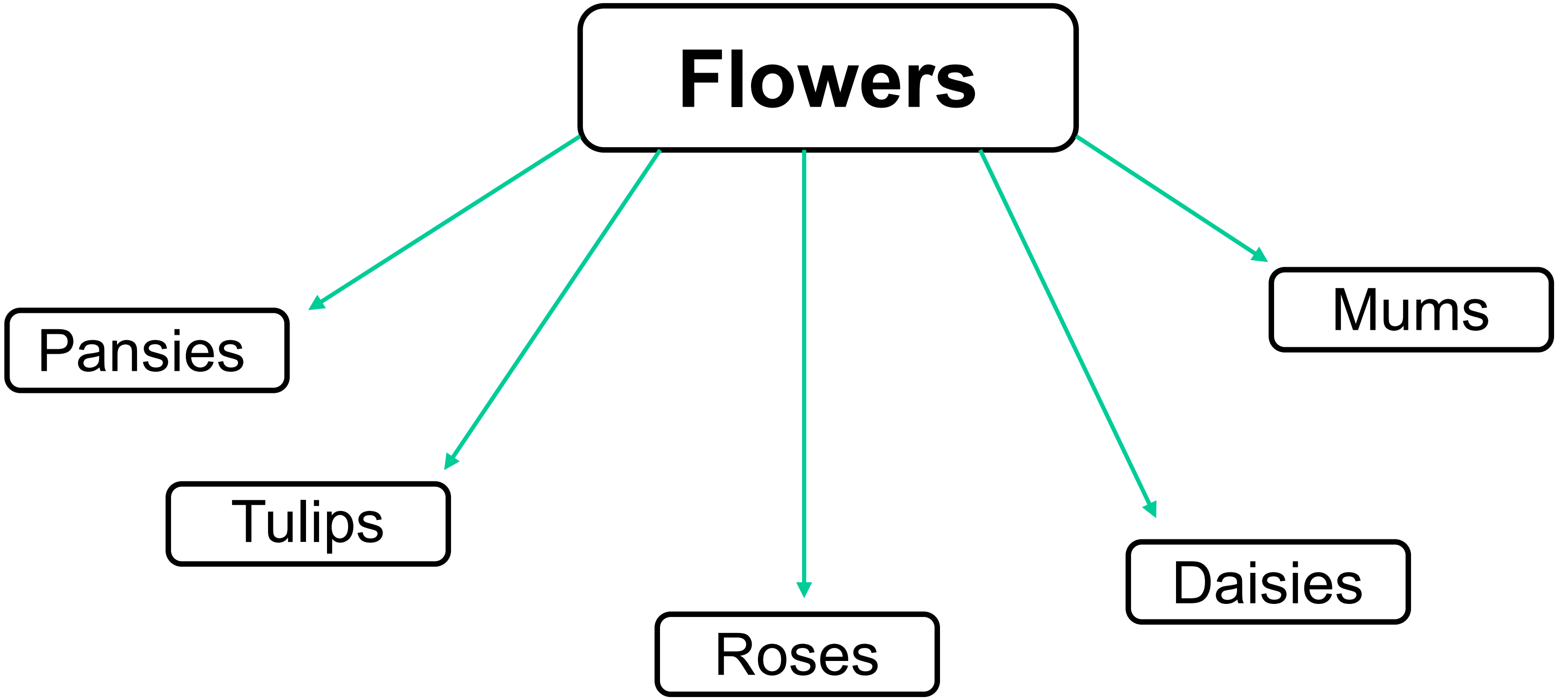
- **What Is Dementia / Alzheimer's Disease?**
- Facts / Figures on Dementia / Alzheimer's
- Challenges Faced by Caregivers
- My Journey as a Care Partner for my Wife, Sumi Who has Younger Onset of Alzheimer's
- Lessons Learned as Care Partner for Sumi

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

Source: Alzheimer's Association - Michigan

Alzheimer’s Journey – As a Care Partner
Dementia and Flowers Metaphor



Flowers

Pansies

Tulips

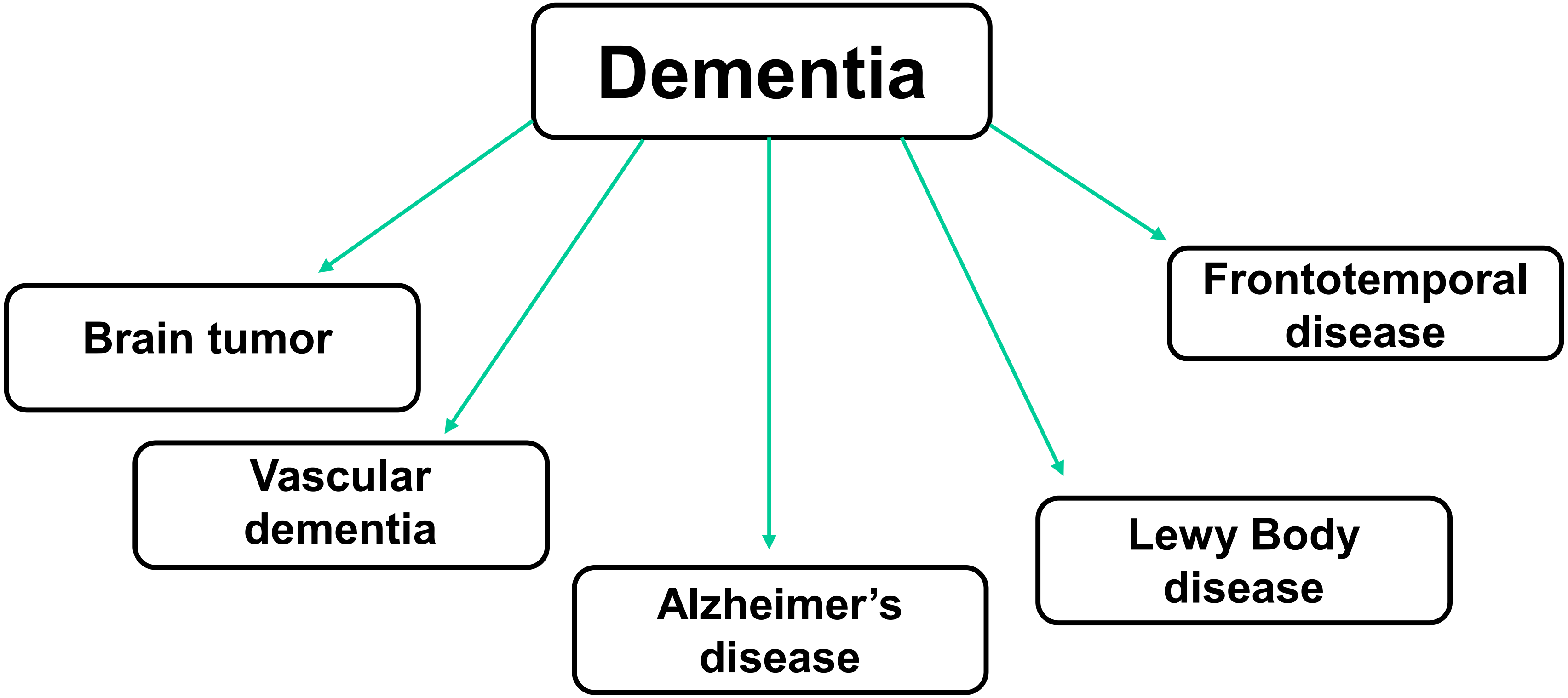
Roses

Daisies

Mums

Source: Alzheimer’s Association - Michigan

Alzheimer's Journey – As a Care Partner
Types of Dementia



Dementia

- **Brain tumor**
- **Vascular dementia**
- **Alzheimer's disease**
- **Lewy Body disease**
- **Frontotemporal disease**

Source: Alzheimer's Association - Michigan

What Is Alzheimer's Disease?

- The most common form of dementia
- A disease of the brain that destroys brain cells, causing problems with memory, thinking, and behavior
- Progressive disease with no cure that is eventually fatal

Source: Alzheimer’s Association - Michigan

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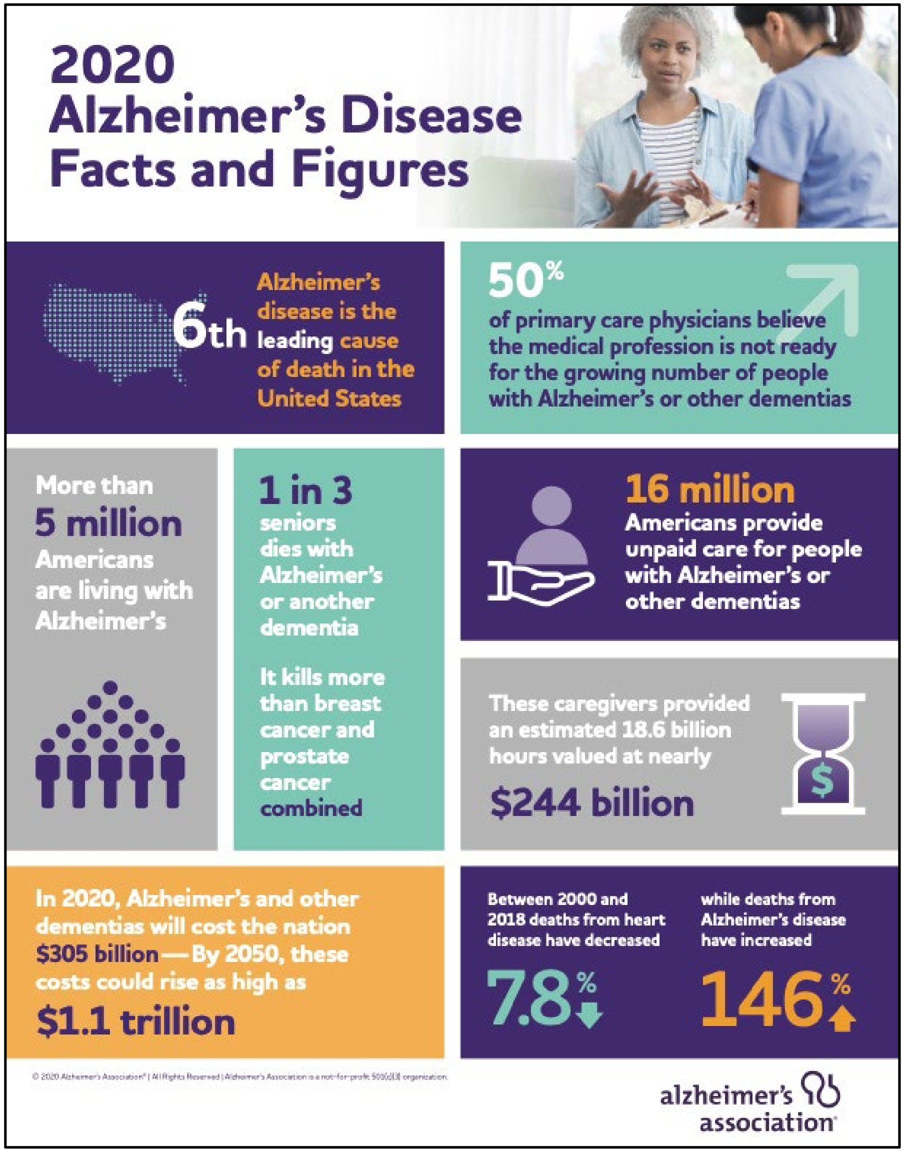
Alzheimer's Journey – As a Care Partner
USA – 2020 Alzheimer's Disease Facts and Figures

- **An estimated 5.8 million Americans age 65 and older have Alzheimer's dementia,**
- **16 million American provide unpaid care for people with Alzheimer's or other dementia**
  - **Totaling 18.6 billion hours**
  - **Valued at $244 billion**
- **1 in 3 seniors dies from Alzheimer's / dementia. It kills more than breast cancer or prostate cancers**
- **Deaths due to Alzheimer's have increased 146% since 2000, while deaths for most other major diseases remained flat or decreased.**
- **In 2020, Alzheimer's / dementia will cost nation $305 billion. In 20250 it could rise to $1.1 trillion**

Source: Alzheimer's Association Michigan



2020 Alzheimer's Disease Facts and Figures

6th Alzheimer's disease is the leading cause of death in the United States

50% of primary care physicians believe the medical profession is not ready for the growing number of people with Alzheimer's or other dementias

More than **5 million** Americans are living with Alzheimer's

1 in 3 seniors dies with Alzheimer's or another dementia

It kills more than breast cancer and prostate cancer combined

16 million Americans provide unpaid care for people with Alzheimer's or other dementias

These caregivers provided an estimated 18.6 billion hours valued at nearly **$244 billion**

In 2020, Alzheimer's and other dementias will cost the nation $305 billion — By 2050, these costs could rise as high as **$1.1 trillion**

Between 2000 and 2018 deaths from heart disease have decreased **7.8%**

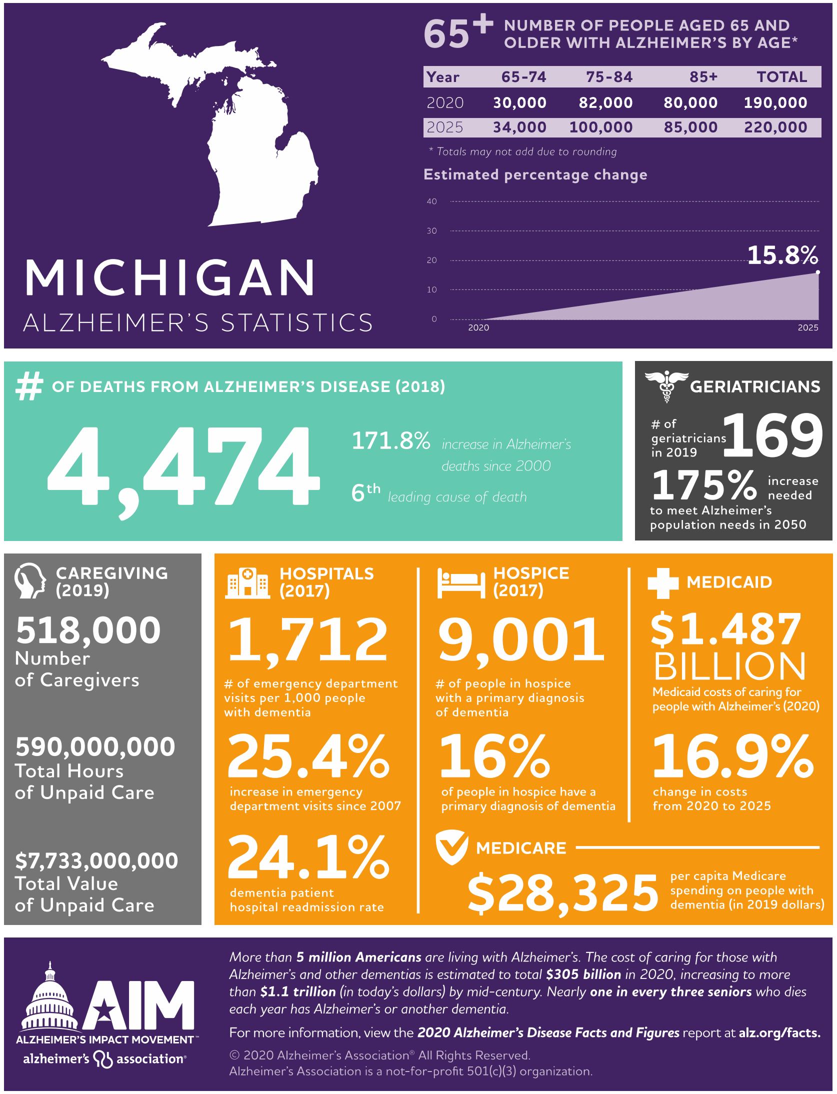
while deaths from Alzheimer's disease have increased **146%**

alzheimer's association

Alzheimer's Journey – As a Care Partner
Michigan – 2020 Alzheimer's Disease Facts and Figures

For Michigan

- **Michigan has 190,000 people with Alzheimer's**
- **518,000 caregivers provided a total of 590 million hours of unpaid care, valued at a total of $7.7 billion**
- **Total lifetime cost of care could exceed $350,000**
- **4,474 total death (172% increase) due to Alzheimer's in Michigan in 2018**
- **The Medicaid costs of caring for people with Alzheimer's is estimated at $1.5 billion**



MICHIGAN
ALZHEIMER'S STATISTICS

65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE*

Year	65-74	75-84	85+	TOTAL
2020	30,000	82,000	80,000	190,000
2025	34,000	100,000	85,000	220,000

** Totals may not add due to rounding*

Estimated percentage change

 # OF DEATHS FROM ALZHEIMER'S DISEASE (2018)

4,474

171.8% *increase in Alzheimer's deaths since 2000*

6th *leading cause of death*

GERIATRICIANS

# of geriatricians in 2019 **169**

175% increase needed to meet Alzheimer's population needs in 2050

CAREGIVING (2019)

518,000 Number of Caregivers

590,000,000 Total Hours of Unpaid Care

$7,733,000,000 Total Value of Unpaid Care

HOSPITALS (2017)

1,712 # of emergency department visits per 1,000 people with dementia

25.4% increase in emergency department visits since 2007

24.1% dementia patient hospital readmission rate

HOSPICE (2017)

9,001 # of people in hospice with a primary diagnosis of dementia

16% of people in hospice have a primary diagnosis of dementia

MEDICAID

$1.487 BILLION Medicaid costs of caring for people with Alzheimer's (2020)

16.9% change in costs from 2020 to 2025

MEDICARE

$28,325 per capita Medicare spending on people with dementia (in 2019 dollars)

AIM
ALZHEIMER'S IMPACT MOVEMENT™
alzheimer's association®

More than ***5 million Americans*** *are living with Alzheimer's. The cost of caring for those with Alzheimer's and other dementias is estimated to total* ***$305 billion*** *in 2020, increasing to more than* ***$1.1 trillion*** *(in today's dollars) by mid-century. Nearly* ***one in every three seniors*** *who dies each year has Alzheimer's or another dementia.*

For more information, view the ***2020 Alzheimer's Disease Facts and Figures*** report at **alz.org/facts.**

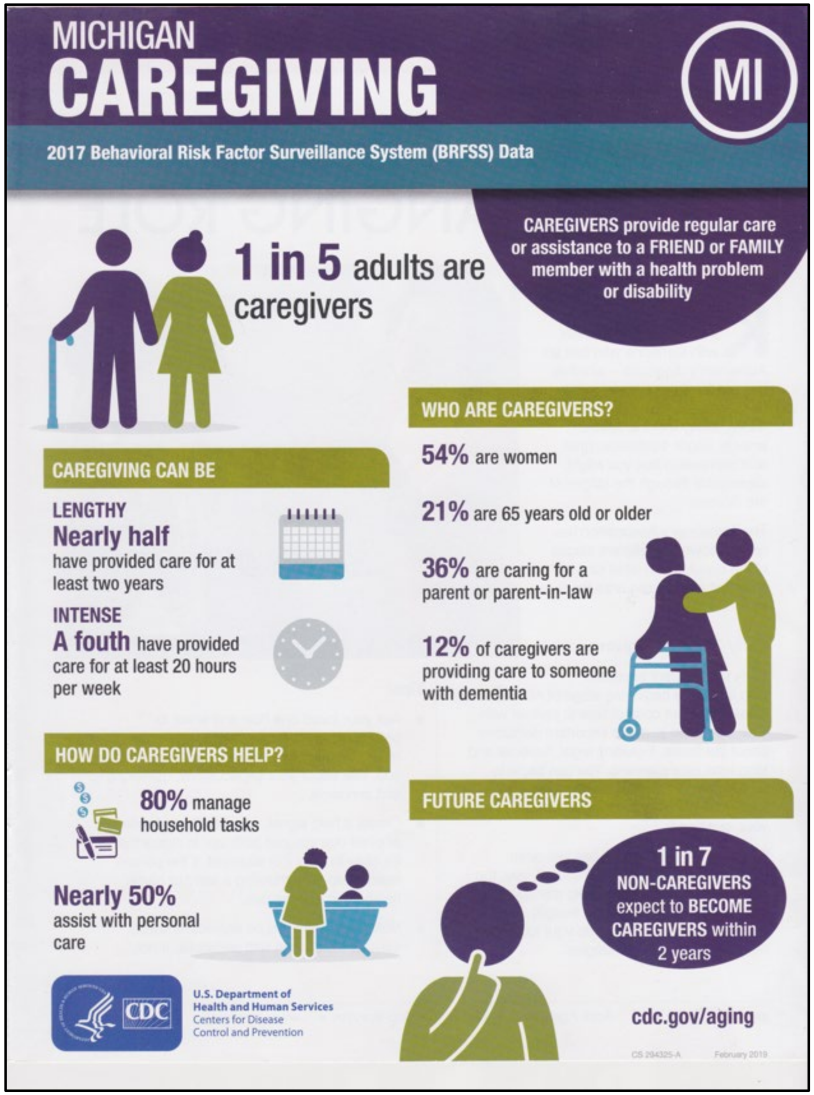
Source: Alzheimer's Association Michigan

Alzheimer's Journey – As a Care Partner
Michigan Caregiving Profiles – Facts and Figures

Michigan Caregiving

1 in 5 adults are caregivers

- Nearly 50% have provided care for at least 2 years
- 25% have provided care for or 20 hours per week
- 85% manage household chores
- 50% assist with personal care
- 1 in 7 non-caregivers expect to become caregivers within 2 years



MICHIGAN
CAREGIVING
MI

2017 Behavioral Risk Factor Surveillance System (BRFSS) Data

1 in 5 adults are caregivers

CAREGIVERS provide regular care or assistance to a FRIEND or FAMILY member with a health problem or disability

CAREGIVING CAN BE

LENGTHY
Nearly half have provided care for at least two years

INTENSE
A fouth have provided care for at least 20 hours per week

WHO ARE CAREGIVERS?

54% are women

21% are 65 years old or older

36% are caring for a parent or parent-in-law

12% of caregivers are providing care to someone with dementia

HOW DO CAREGIVERS HELP?

80% manage household tasks

Nearly 50% assist with personal care

FUTURE CAREGIVERS

1 in 7 NON-CAREGIVERS expect to BECOME CAREGIVERS within 2 years

CDC
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

cdc.gov/aging

CS 294325-A February 2019

Source: Connect Magazine - Area Agency on Aging 1-B - Michigan

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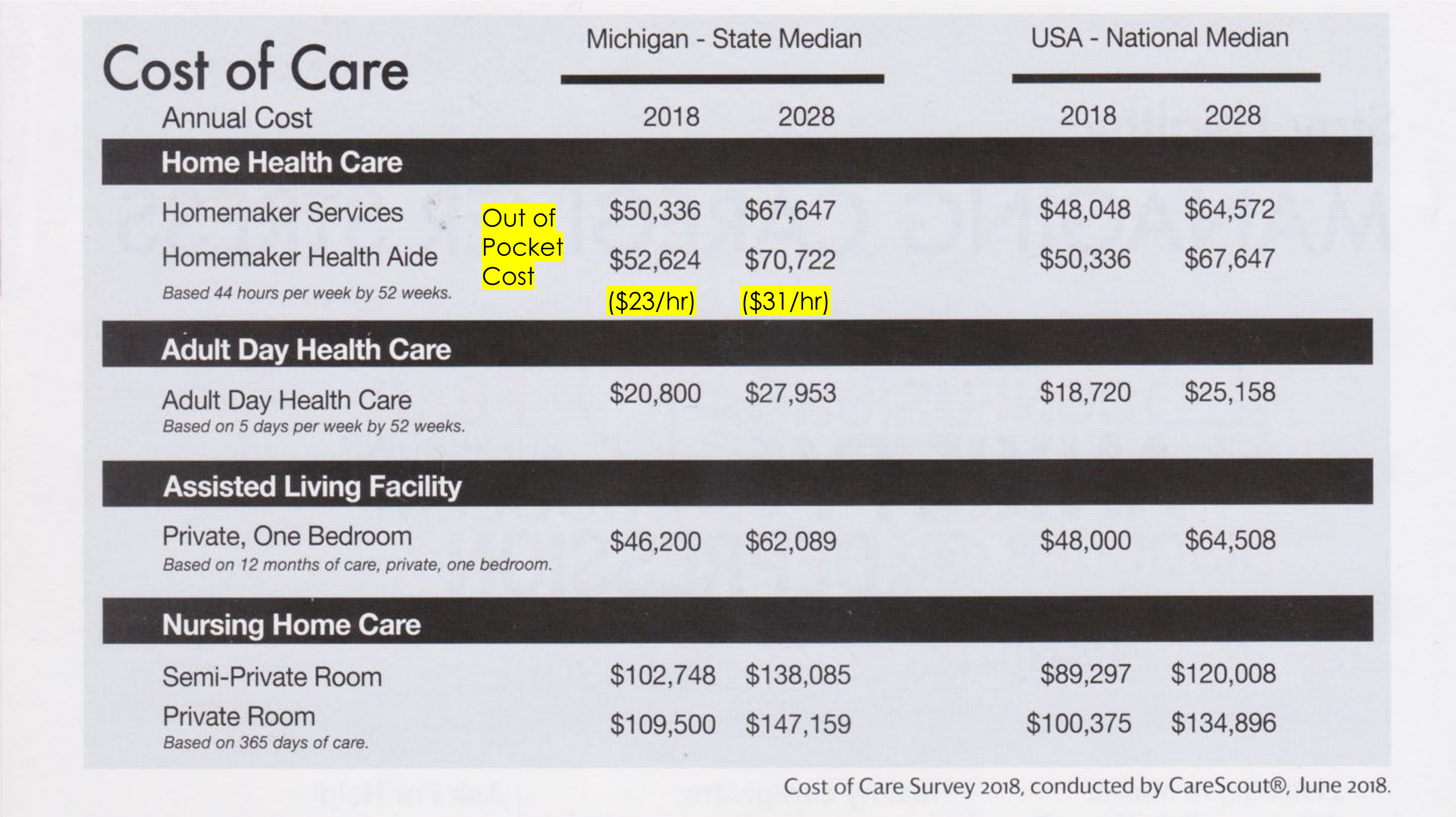
Alzheimer’s Journey – As a Care Partner
Emotional Challenges Faced by Care Givers - Managing Caregiver Stress

Stay Healthy: Managing Caregiver Stress

Source: Connect Magazine - Area Agency on Aging 1-B - Michigan

Alzheimer's Journey – As a Care Partner
Cost of Care



Cost of Care

Annual Cost		Michigan - State Median		USA - National Median	
		2018	2028	2018	2028
Home Health Care					
Homemaker Services	Out of Pocket Cost	$50,336	$67,647	$48,048	$64,572
Homemaker Health Aide		$52,624	$70,722	$50,336	$67,647
Based 44 hours per week by 52 weeks.		($23/hr)	($31/hr)		
Adult Day Health Care					
Adult Day Health Care *Based on 5 days per week by 52 weeks.*		$20,800	$27,953	$18,720	$25,158
Assisted Living Facility					
Private, One Bedroom *Based on 12 months of care, private, one bedroom.*		$46,200	$62,089	$48,000	$64,508
Nursing Home Care					
Semi-Private Room		$102,748	$138,085	$89,297	$120,008
Private Room *Based on 365 days of care.*		$109,500	$147,159	$100,375	$134,896

Cost of Care Survey 2018, conducted by CareScout®, June 2018.

Source: Connect Magazine - Area Agency on Aging 1-B - Michigan

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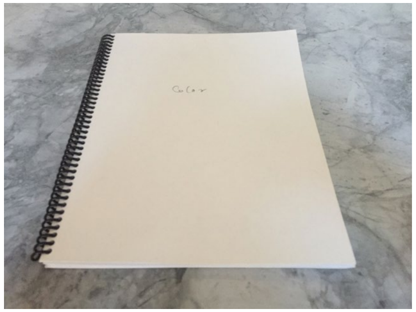
Alzheimer’s Journey – As a Care Partner
My blog – My Journey with Sumi (1/2)

My Journey as a Care Partner

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

In May 2020, she will turn 66. We have been married for 45 years. I would like to share things I have learned in these seven years about Alzheimer’s disease and being a care partner.

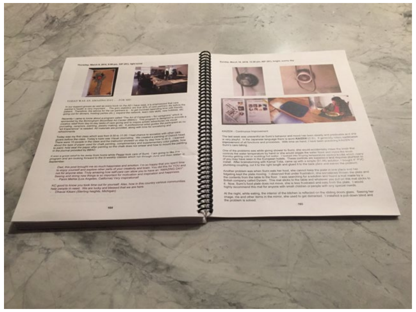
Since February 14, 2017 (Valentine’s Day), I have been writing an online journal called, My Journey with Sumi (MJWS), on WhatsApp to channel my feelings and share with close family and friends to keep them updated by offering a glimpse into our lives. I write “in the Moment” without much dwelling on it or fine tuning. It helps me process my emotions and I find it therapeutic



I have written about 86,000 words on MJWS and from this writing I have composed about 20 stand-alone essays comprising of about 23,000 words.

My three main objectives of writing were:

1. Increase awareness of Alzheimer’s disease.
2. Share our lives, my thoughts and feelings with family and friends.
3. Let my my writing be a barometer of my ‘state of mind.” When - or if - in the future I falter, it could be an indication that I am not doing well and need help.



Alzheimer’s Journey – As a Care Partner
My blog – My Journey with Sumi (1/2)

My Journey as a Care Partner

Lately, my writing is being recognized and I would like to share the following to provide additional insight into My Journey:

- The Area Agency on Aging 1-B (Michigan), had organized Caregiver Champions story contest in October 2019. My story won for the Oakland county where I am living.

- I was interviewed by The Indian Scene, an online magazine and a 2-part articles appeared capturing various aspects of Alzheimer’s and how it has affected our lives.
  Part 1 (Love, Care and Life Changing Diagnosis - The Indian Scene, November 13, 2019)
  https://theindianscene.com/health/love-care-and-a-life-changing-diagnosis-a-story-of-alzheimers-disease/

  Part 2 (Adjusting to a new normal - a story of Alzheimer’s disease - The Indian Scene, November 24, 2019)
  https://theindianscene.com/health/adjusting-to-a-new-normal-a-story-of-alzheimers-disease/

- I was interviewed by Dr. Subhash Kelkar of Geetanjali radio program in which I discussed Sumi’s Alzheimer’s disease. The interview gave a voice (in a literal sense as well) to Sumi and my Journey. Geetanjali caters to the metro Detroit's Indian American community. The interview was aired on November 23 on WPON, AM 1460 radio station.

- I was interviewed by Mrs. Danialle Karmanos for her podcast called “Karma Has Spoken” on November 18, 2019 which went online on February 5, 2020. Link below will take you to the podcast and the interview. There are 2 interviews on the 50.56 min podcast. My interview is for about 43 minutes and it begins at the mark of 8:10 minute.
  https://karmahasspoken.com/podcast/author-karen-buscemi-and-alzheimers-advocate-kc-mehta/

- The Blue Cross Blue Shield of Michigan published a 3-part articles on My Journey with Sumi on March 18, 19 and 20.
  https://www.ahealthiermichigan.org/2020/03/18/sumis-smile-a-caregiving-love-story/
  https://www.ahealthiermichigan.org/2020/03/19/sumi-2-0-becoming-sumis-care-partner/
  https://www.ahealthiermichigan.org/2020/03/20/coping-as-sumis-caregiver/

- Wayne State University’s Department of Gerontology has been serializing about 20 essays from My Journey with Sumi on their website.

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Alzheimer’s Journey – As a Care Partner
Scaling a Challenging Mountain

My Journey as a Care Partner

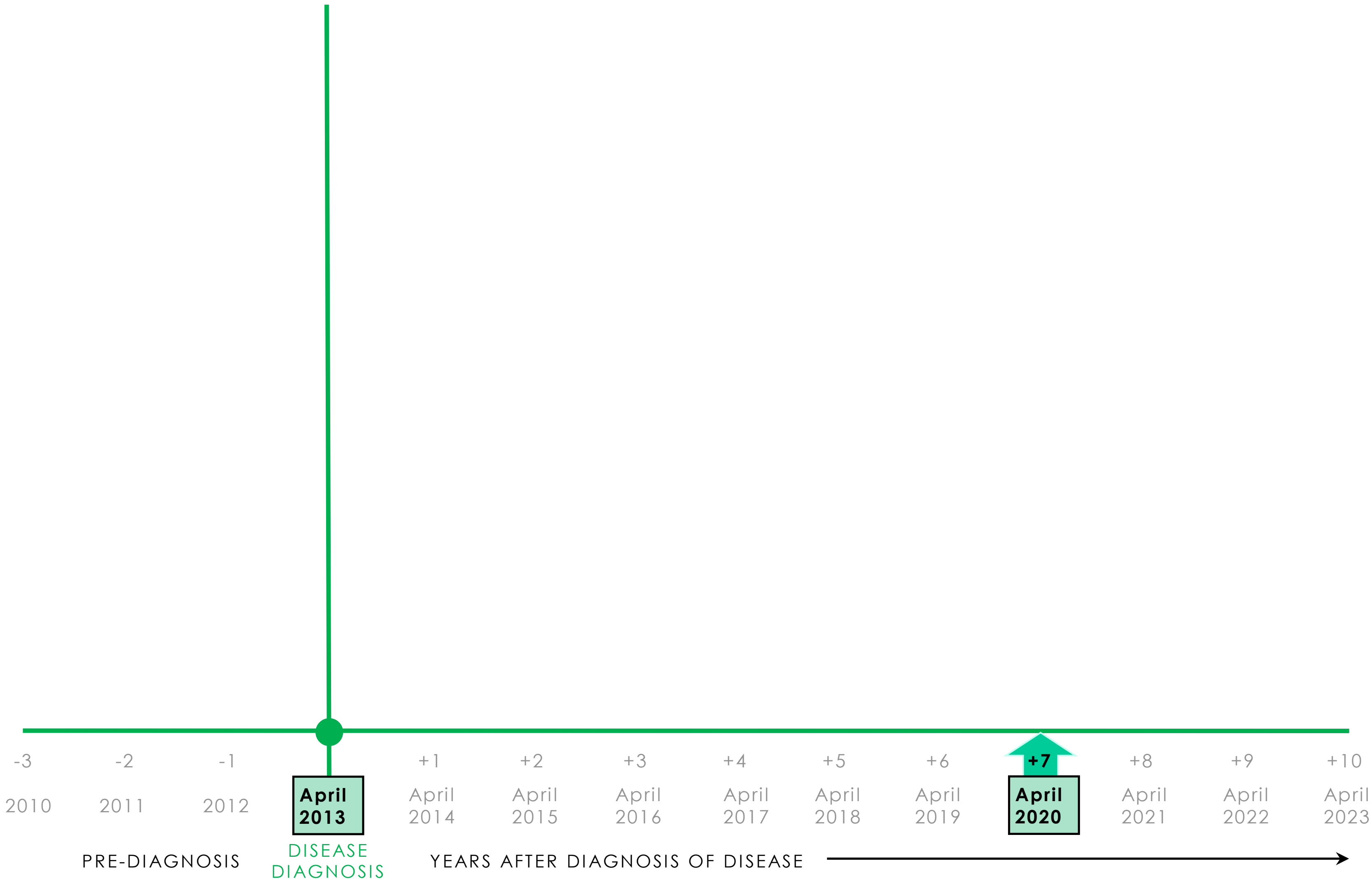
As care partners or care givers, we all are attempting to scale a challenging mountain. In my 7 years of Journey, I happen to be at a greater height on the mountain and have learned a thing or two along the way. Whereas, other caregivers could be in the early stages of their journey, at a lesser height.

Terms to Know

A person with the disease, or PWD, is someone like Sumi who has Alzheimer’s disease.

A care partner is someone like me who is a spouse devoted to helping and caring for a PWD.

Alzheimer’s Journey – Average Life Expectancy



-3	-2	-1		+1	+2	+3	+4	+5	+6	**+7**	+8	+9	+10
2010	2011	2012	**April 2013**	April 2014	April 2015	April 2016	April 2017	April 2018	April 2019	**April 2020**	April 2021	April 2022	April 2023

PRE-DIAGNOSIS

DISEASE DIAGNOSIS

YEARS AFTER DIAGNOSIS OF DISEASE →

(THE LIFE EXPECTANCY OF THE PWD VARIES BASED ON VARIOUS FACTORS. AFTER DIAGNOSIS AVERAGE LIFE EXPECTANCY IS 8 TO 10 YEARS)

* Source: Alzheimer’s Association

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Alzheimer’s Journey – Average Life Expectancy

My Journey as a Care Partner

On the previous page, I’ve charted the years of Sumi’s life expectancy. Marked with a green vertical line is the time of diagnosis, in April 2013. Since there is usually 1 to 3 years, or more of symptoms present before diagnosis (pre-early stage) I have included those years on the left. On the right, for simplicity sake, I have chosen a 10-year life expectancy.

The average life expectancy after diagnosis is 8 to 10 years.
However, some cases show it can be as short as 3 years or as long as 20.

Life expectancy depends of many factors, such as:

- **Age at the time of diagnosis:** This factor has the greatest impact on life expectancy.
  - The average survival time for those diagnosed at age 65 is 8.3 years.
  - The average life expectancy for those diagnosed at age 90 is 3.4 years.
- **Gender:** Women tend to live 1.5 years longer than men after diagnosis.
- **Other health problems:** Those with heart disease, a history of heart attack, and diabetes have shorter lifespans.
- **Severity of symptoms.** Those who have significant motor impairment, a history of falls, and a tendency to wander show shorter life expectancies.
- **Brain abnormalities:** Brain and spinal cord abnormalities shorten life expectancy.
- **Quality of care:** In my wife’s case, one-on-one, person-centered care at home has been beneficial to her vs. out-sourced care at a nursing home where one caregiver is taking care of multiple PWDs.

- Source: Healthline Support (https://www.healthline.com/health/alzheimers-disease/life-expectancy)

3-Stages* of Alzheimer's Disease

* Source: Alzheimer's Association

Three Stages of Person with the Alzheimer's Disease*
Currently Sumi exhibits items highlighted in yellow

Early Stage

Problems coming up with the right word or name

Trouble remembering names when introduced to new people

Challenges performing tasks in social or work settings.

Forgetting material that one has just read

Losing or misplacing a valuable object

Increasing trouble with planning or organizing

Middle Stage

Forgetfulness of events or about one's own personal history

Feeling moody or withdrawn, especially in socially or mentally challenging situations

Being unable to recall their own address or telephone number or the high school or college from which they graduated

Confusion about the day / where they are

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

Trouble controlling bladder and 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

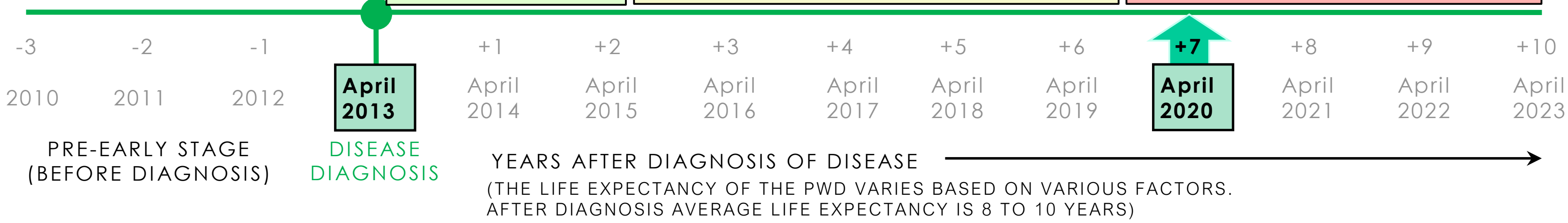
Need round-the-clock assistance with daily activities and personal care

Lose awareness of recent experiences as well as of their surroundings

Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow

Have increasing difficulty communicating

Become vulnerable to infections, especially pneumonia



-3	-2	-1		+1	+2	+3	+4	+5	+6	**+7**	+8	+9	+10
2010	2011	2012	**April 2013**	April 2014	April 2015	April 2016	April 2017	April 2018	April 2019	**April 2020**	April 2021	April 2022	April 2023

PRE-EARLY STAGE
(BEFORE DIAGNOSIS)

DISEASE DIAGNOSIS

YEARS AFTER DIAGNOSIS OF DISEASE →

(THE LIFE EXPECTANCY OF THE PWD VARIES BASED ON VARIOUS FACTORS. AFTER DIAGNOSIS AVERAGE LIFE EXPECTANCY IS 8 TO 10 YEARS)

* Source: Alzheimer's Association

Three Stages of Person with the Alzheimer's Disease*
Currently Sumi exhibits items highlighted in yellow

My Journey as a Care Partner

Three Stages of Alzheimer's Disease* (with Sumi's Behaviors Highlighted)
The Alzheimer's Association has defined the progress of Alzheimer's in three stages—early, middle, and late. Within these stages there isn't a clear demarcation of traits exhibited by the PWD.

As Sumi's assumed life expectancy is chosen as ten years, the duration of three stages could be broken down as:

- Early stage: Up to 2 years
- Middle stage: 5 years (2 to 7 years)
- Late stage: 3 years (8 to 10 years)

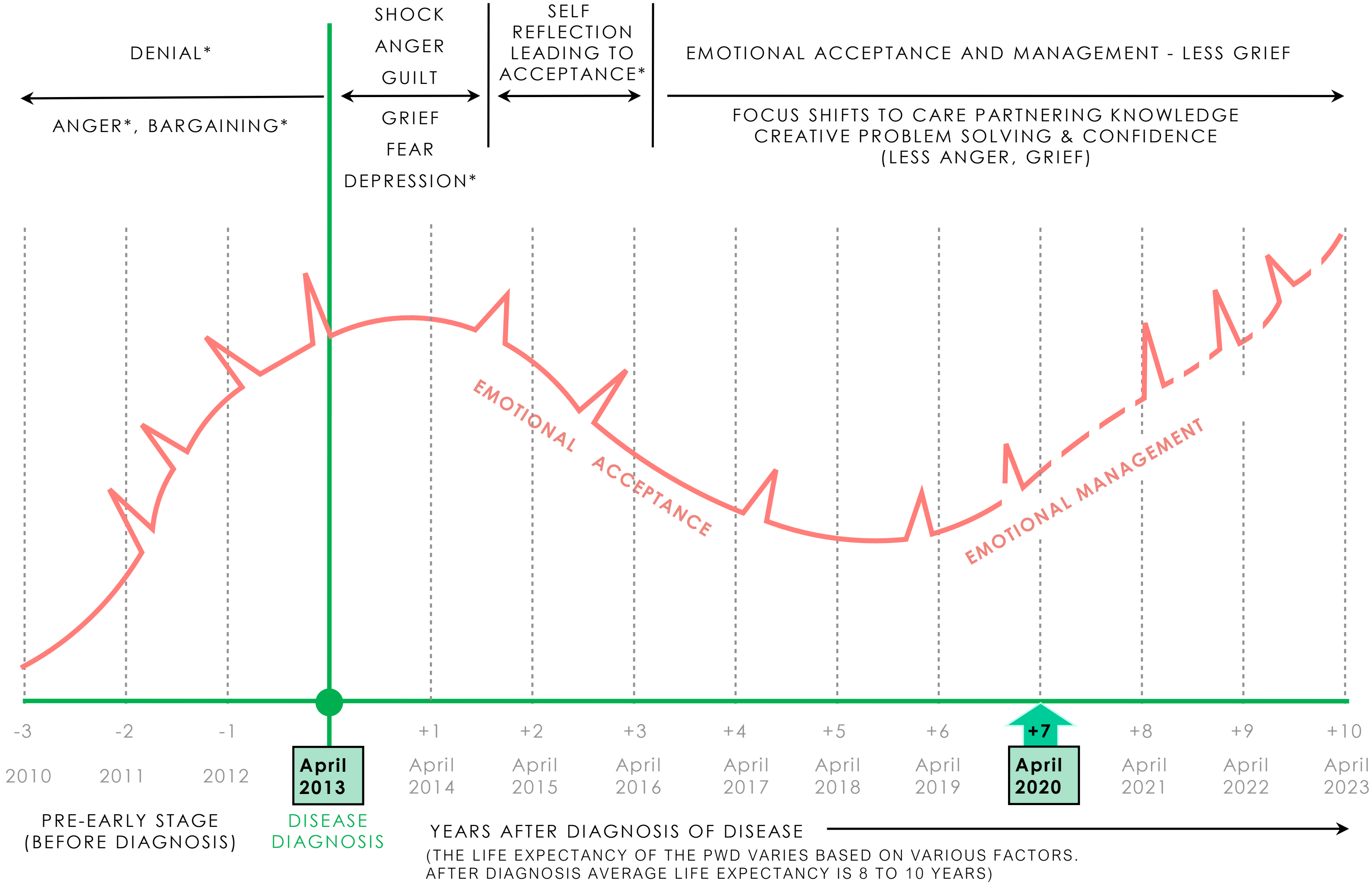
If the life expectancy of the PWD is less than 10 years, then these three stages would be compressed and vice versa.

Over the years, Sumi has migrated from the early stage to exhibiting most of the items for the middle stage and some items from the late stage. In the chart I highlighted the behaviors Sumi exhibits, such as:

- Trouble controlling her bladder and bowls (incontinency).
- Needing round-the-clock assistance with daily activities.
- Lost awareness of recent experiences as well as her surroundings.
- Not able to communicate her needs, discomfort and pain.

However, Sumi is physically fit without any other ailments or needing any medications. She eats well and walks 3 to 4 miles in our basement every day.

My (as a Care Partner's) Alzheimer's Disease Journey Curve with Emotional Acceptance and Management with Frequent "Emotional Tremors"



DENIAL*

ANGER*, BARGAINING*

SHOCK
ANGER
GUILT
GRIEF
FEAR
DEPRESSION*

SELF REFLECTION LEADING TO ACCEPTANCE*

EMOTIONAL ACCEPTANCE AND MANAGEMENT - LESS GRIEF

FOCUS SHIFTS TO CARE PARTNERING KNOWLEDGE
CREATIVE PROBLEM SOLVING & CONFIDENCE
(LESS ANGER, GRIEF)

PRE-EARLY STAGE
(BEFORE DIAGNOSIS)

DISEASE DIAGNOSIS

YEARS AFTER DIAGNOSIS OF DISEASE

(THE LIFE EXPECTANCY OF THE PWD VARIES BASED ON VARIOUS FACTORS. AFTER DIAGNOSIS AVERAGE LIFE EXPECTANCY IS 8 TO 10 YEARS)

* Kubler Ross – Stages of Grief

My (as a Care Partner's) Alzheimer's Disease Journey Emotional Curve (1/6)

My Journey as a Care Partner

As part of a normal and slow aging process we change physically, biologically, emotionally, and mentally. We become wiser and our views on many topics evolve or change. We tend to appreciate the shades of gray in many situations versus our younger-selves who focus on the black and white.

When Sumi was first diagnosed with Alzheimer's all these changes were thrust upon our family at an unnatural and rapid rate. Just like me, most are not prepared for it.

For the first three years after Sumi was diagnosed, I went through many phases:

- Denial, in that I hoped the neurologist may have misdiagnosed the disease as Alzheimer's vs. mild cognitive impairment
- Research, where I read at least 15 books on Alzheimer's disease
- Soul-searching
- Self-analysis
- Reflection

Slowly, I came to realize that hoping the PWD would change is futile. The changes needed to happen in me.

My (as a Care Partner's) Alzheimer's Disease Journey Emotional Curve (2/6)

My Journey as a Care Partner

Ultimately, from my reading I learned about two types of caring:

- Caring for: which are things I can do for Sumi to better her care.
- Caring with: which are things Sumi and I can do together for her care.

Both types of caring are equally important. If Sumi is unable to do something for herself, I can step in and do it for her. But if she is able to perform or help with a task we work together.

Caring with, rather than caring for, has been an effective way to handle and manage Sumi. It cultivates love, mercy, compassion, and patience. It has taught me to 'control the controllable and manage the uncontrollable.'

I have also come to realize there are two aspects of effective caretaking:

- Creative problem-solving
- Emotional acceptance - Leads to emotional management.

Creative problem-solving means employing devices, gadgets, technology, etc. to make Sumi's life safe and comfortable.

Whereas, emotional acceptance and management means recognizing that Sumi is slowly changing in front of me. And that sooner or later it becomes incumbent upon me to change as well. Sumi is not a problem to be solved but someone to be cared for deeply with love, compassion, patience, and mindfulness.

My (as a Care Partner's) Alzheimer's Disease Journey Emotional Curve (3/6)

My Journey as a Care Partner

Prior to Sumi's diagnosis, our relationship was binary and reciprocal. We took care of each other's needs and there was mutual dependency. Our tasks of running the house were divided to each other's' skills and comfort level.

With the onset of the disease, everything turned upside-down. Our relationship, in most situations, has become unidirectional and non-reciprocal. My love for Sumi has become more 'intentional.' It is not easy to naturally love when under a lot of stress and pushed into frustrating situations. And in some demanding situations reflexes take over.

Gradually, I started to differentiate and accept the changes in Sumi. When she is extremely difficult it is not her, but the disease. And when she smiles it is her true self and not the disease.

The above transformation in me, her care partner, happened over almost three years. For a long time I thought about a way to graphically show these changes and so I developed illustrations that depict our Journey on a timeline basis.

Each PDW and their care partner have unique circumstances and journeys. What transpired for me and Sumi could be totally different for others. However, there are many general paths that most PWDs and their care partners end up following. All these paths can be depicted in many ways. There are no hard and fast rules. What fits one situation might not fit others.

My (as a Care Partner's) Alzheimer's Disease Journey
Emotional Curve (4/6)

Emotional Acceptance and Management Curve

The illustration on the previous page shows the Emotional Curve that occurs in a care partner when taking care of the PWD. The horizontal x-axis shows the years of life expectancy of the PWD. The vertical y-axis has no scale but shows the magnitude of the emotions experienced by the care partner.

In Sumi's case, the symptoms of the disease were present at least 3 years before medical diagnosis. I call this the pre-early stage. During this phase, generally, there is denial and anger in both the PWDs and their care partners.

I was in denial more than angry. Sumi tried to come to grips with what was happening. She would ask, "Why me?"

The Emotional Curve, for us, was at its peak just before and after diagnosis.
After diagnosis, the PWD and their care partners may go through shock, anger, guilt, grief, fear, and sometimes depression.

This disease causes suffering in both the PWD and their care partners. For care partners, the suffering is at a heightened level in the early years and can last throughout the journey at various degrees of intensities as the disease progresses and the PWD changes.

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My (as a Care Partner's) Alzheimer's Disease Journey Emotional Curve (5/6)

Emotional Acceptance and Management Curve

I was not in shock, anger, or depression but mostly in grief and guilt. Guilt in that all through our lives Sumi was such a good wife to me and I could have been a better husband to her.

After this peak, I started to reflect about our situation and figure out how to handle it. This led to my emotional acceptance and management of Sumi's disease. As I saw Sumi change, I knew I needed to change my perspective as well. I began to differentiate between the times Sumi was acting because of the disease and when she was her true smiling self. As my focus shifted more to caregiving, though, I found real or anticipatory grief had been present throughout my journey.

The Emotional Curve is not smooth. It has episodes of sudden changes to reflect the sudden changes in the care partner's emotions. This could be from an increased difficulty of managing the PWD or from other events happening in the care partner's life. I call these outbursts of emotions 'emotional tremors.'

As the disease progressed to the middle stage, which was from 3 to 6 years after diagnosis, my Emotional Curve flattened out. This is because I gained knowledge about the disease through reading, attending support groups, going to seminars, and observing professional caretakers.

My (as a Care Partner’s) Alzheimer’s Disease Journey
Emotional Curve (6/6)

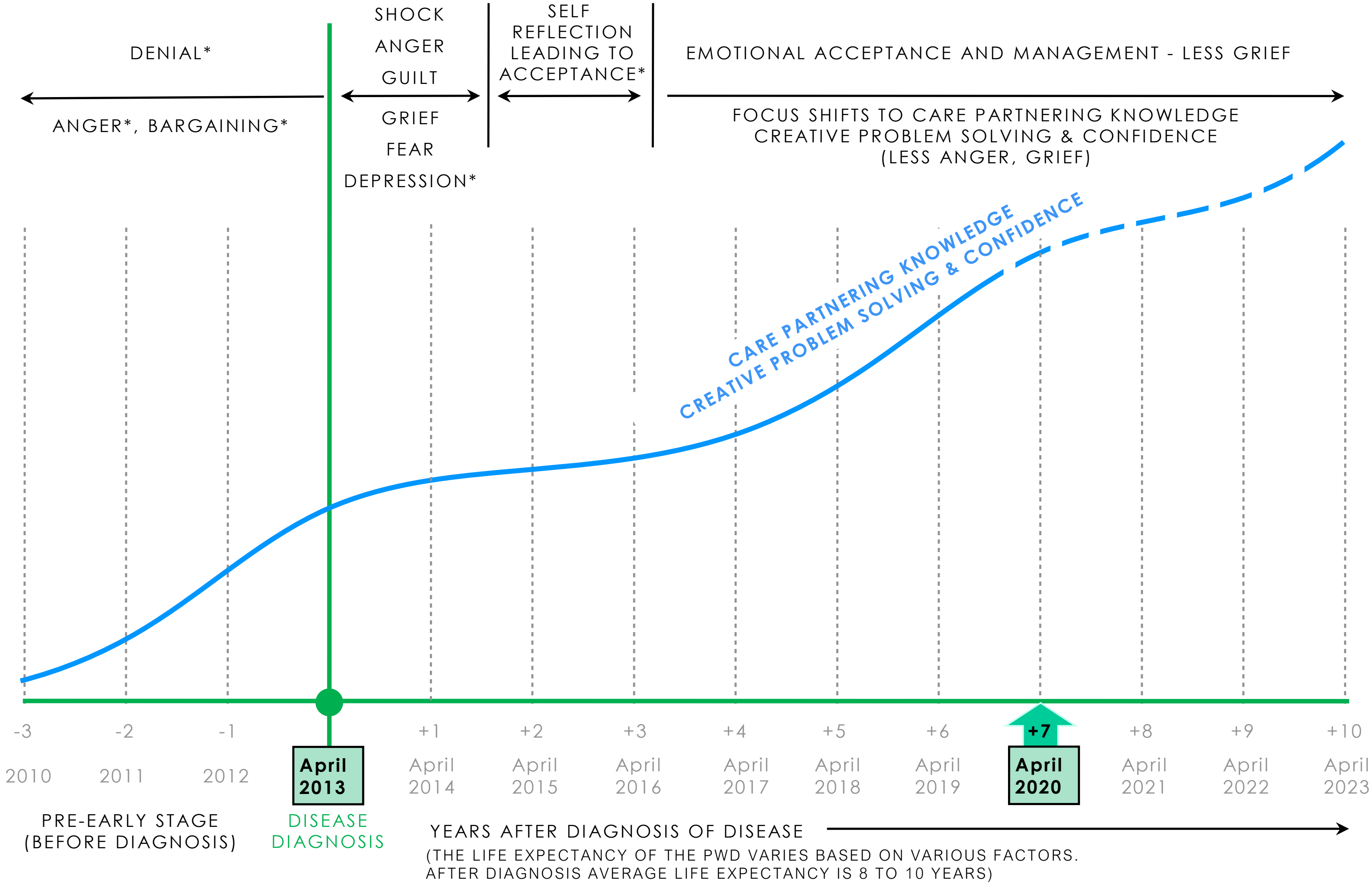
Emotional Acceptance and Management Curve

Knowledge was also gained by seeking wisdom through contemplation, mindfulness, learning to live in the present, finding a sense of equanimity and proportion, and understanding the impermanence in nature. Above all, writing and sharing with family and friends about our lives, my thoughts, and my feelings helped a lot.

I know that ultimately, the Emotional Curve will shoot up when Sumi enters the late stage of the disease.

In the final stage the brain’s functions deteriorate so much that it fails to instruct the mouth to chew and swallow which results in more complications and deterioration in health. This will cause heightened emotional distress for loved ones and care partners as the ultimate demise of the PWD becomes a reality.

My (as a Care Partner’s) Alzheimer’s Disease Journey
Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence



DENIAL*

ANGER*, BARGAINING*

SHOCK
ANGER
GUILT
GRIEF
FEAR
DEPRESSION*

SELF REFLECTION LEADING TO ACCEPTANCE*

EMOTIONAL ACCEPTANCE AND MANAGEMENT - LESS GRIEF

FOCUS SHIFTS TO CARE PARTNERING KNOWLEDGE
CREATIVE PROBLEM SOLVING & CONFIDENCE
(LESS ANGER, GRIEF)

CARE PARTNERING KNOWLEDGE
CREATIVE PROBLEM SOLVING & CONFIDENCE

-3 2010
-2 2011
-1 2012
April 2013
+1 April 2014
+2 April 2015
+3 April 2016
+4 April 2017
+5 April 2018
+6 April 2019
+7 April 2020
+8 April 2021
+9 April 2022
+10 April 2023

PRE-EARLY STAGE
(BEFORE DIAGNOSIS)

DISEASE DIAGNOSIS

YEARS AFTER DIAGNOSIS OF DISEASE →
(THE LIFE EXPECTANCY OF THE PWD VARIES BASED ON VARIOUS FACTORS. AFTER DIAGNOSIS AVERAGE LIFE EXPECTANCY IS 8 TO 10 YEARS)

* Kubler Ross – Stages of Grief

My (as a Care Partner's) Alzheimer's Disease Journey
Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence (1/3)

Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence

Care Partnering Knowledge, Strategies, Creative-Problem Solving, and Confidence Curve
A diagram of a second curve is shown on the previous page. This is about the strategies and tactics employed by care partners to take care of the PWD. This ranges from arranging for caregivers to taking care of the PWD's daily chores like toileting, bathing, dressing, feeding etc. It also includes taking care of the legal, financial, and medical matters.

This curve tends to go up steadily as the PWD progresses in the disease because the care partner gains experience and knowledge over time. In their journey, a care partner will come to realize that effective caregiving comes from love, mercy, compassion, and patience.

To me, aside from emotional acceptance and management, being an effective care partner also includes creative problem-solving. With my career as a problem-solving engineer I have invented, designed, and rigged up solutions to aid in Sumi's safety and well-being.

Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence

Some of my solutions are:

- Installing cameras in the house to monitor Sumi's movements.
- Installing a motion sensor alarm in the bedroom so when Sumi tries to get out of bed I am alerted or awaken to tend to her needs.
- Building a ramp from the foyer to our sunken family room to avoid the potential tripping hazard.
- Covering all the mirrors and reflective surfaces in our home to avoid the confusion that comes when Sumi looks into them.
- Changing the carpet in the bedroom to hardwood floor so toilet accidents are easier to clean and lessens my anger and frustrations.
- Putting soft foam pads on any surfaces Sumi could bump in to.
- Rigging up a shroud to go over the shower temperature knobs to prevent accidentally getting splashed with cold or scalding water while showering Sumi.
- Building a ramp from the garage to the house.

This problem-solving aspect of being a care partner gives me small victories. As I test my solutions, it creates a safer and more comfortable environment.

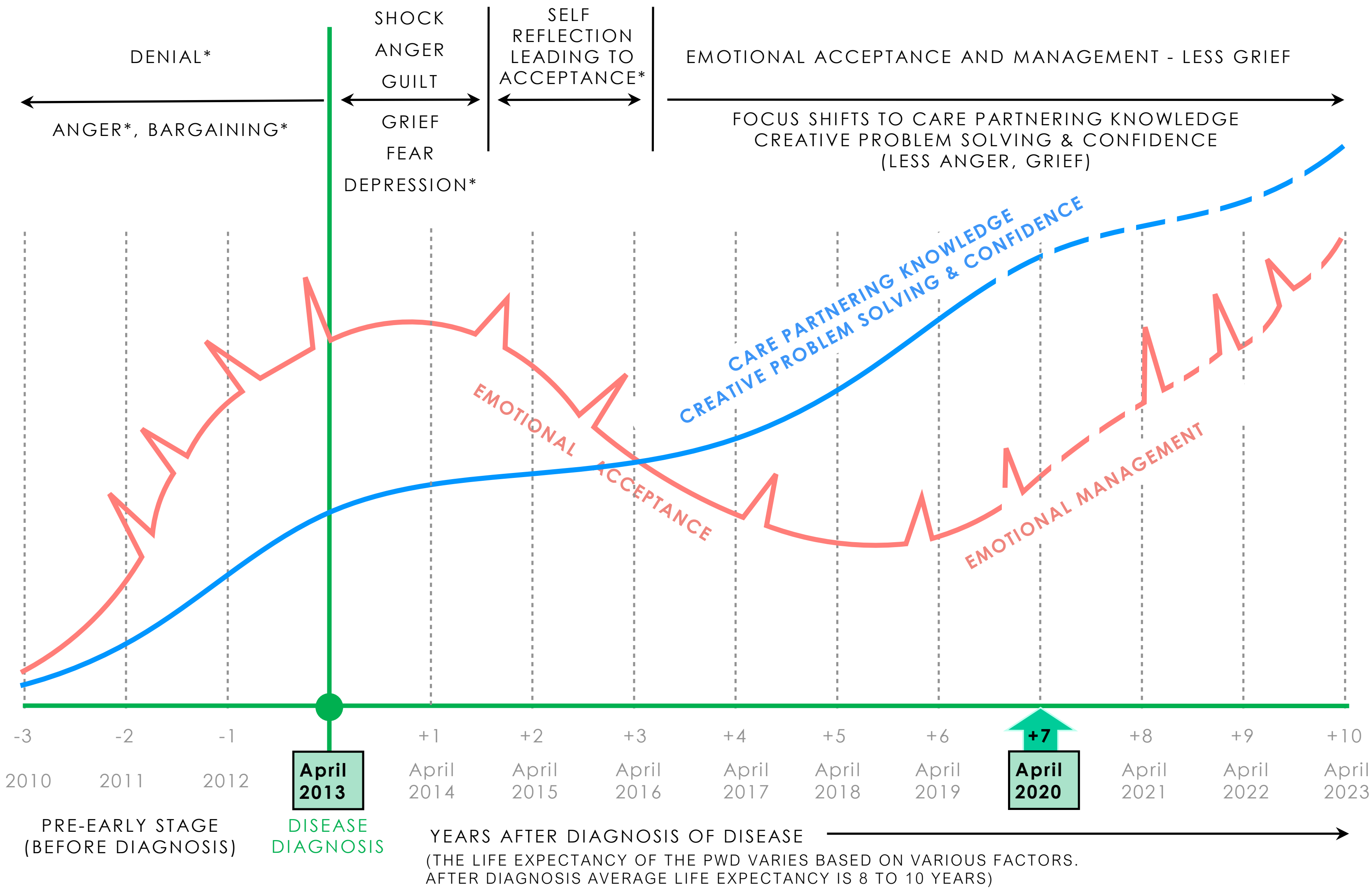
My (as a Care Partner's) Alzheimer's Disease Journey
Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence (3/3)

Garage to
House Ramp

PVC Coupling Over the
Shower Knob

Ramp to the
Sunken Family Room

My (as a Care Partner’s) Alzheimer’s Disease Journey
Emotional Management and Care Partnering Knowledge, Problem Solving & Confidence Curve



(THE LIFE EXPECTANCY OF THE PWD VARIES BASED ON VARIOUS FACTORS. AFTER DIAGNOSIS AVERAGE LIFE EXPECTANCY IS 8 TO 10 YEARS)

* Kubler Ross – Stages of Grief

Agenda

- What Is Dementia / Alzheimer's Disease?
- Facts / Figures on Dementia / Alzheimer's
- Challenges Faced by Caregivers
- My Journey as a Care Partner for my Wife, Sumi Who has Younger Onset of Alzheimer's
- **Lessons Learned as Care Partner for Sumi**

Lessons Learned (1/3):

Combining the Two Curves (Emotional and Care Partnering Strategies and Execution)

To get into some mathematics, the area under the curve represents the amount of that particular item.

The more emotionally inclined a care partner is, it will show a larger area under the Emotional Curve. The more knowledge and understanding of the disease a care partner has will show a larger area under the Care Partnering Strategies Curve. And vice versa.

It's important to note that after diagnoses or after the peak of the Emotional Curve, there is a stretch of time where the Care Partnering Strategies Curve increases as the Emotional Curve decreases. This is because as a care partner gains knowledge of the disease it helps decrease some of the worry and fear of the situation.

Alzheimer's Journey – As a Care Partner
Lessons Learned (2/3)

Lessons Learned (2/3):

There are three stages of Alzheimer's, as published by the Alzheimer's Association– Early, middle and late. Average life expectancy of the PWD is from 8 to 10 years, depending on various factors.

For the first three years after Sumi was diagnosed, I went through many phases:

- Denial, in that I hoped the neurologist may have misdiagnosed the disease as Alzheimer's vs. mild cognitive impairment
- Research, where I read at least 15 books on Alzheimer's disease
- Soul-searching
- Self-analysis
- Reflection

I came to realize that hoping Sumi would change is futile. The changes needed to happen in me.

Ultimately, from my reading I learned about two types of caring:

- Caring for: which are things I can do for Sumi to better her care.
- Caring with: which are things Sumi and I can do together for her care.

Both types of caring are equally important. If Sumi is unable to do something for herself, I can step in and do it for her. But if she is able to perform or help with a task we work together.

Caring with, rather than caring for, has been an effective way to handle and manage Sumi. It cultivates love, mercy, compassion, and patience. It has taught me to 'control the controllable and manage the uncontrollable.'

Alzheimer’s Journey – As a Care Partner
Lessons Learned (3/3)

Lessons Learned (3/3):

I have also come to realize there are two aspects of effective caretaking:

- Creative problem-solving
- Emotional acceptance
  - Leads to emotional management

Creative problem-solving means employing devices, gadgets, technology, etc. to make Sumi’s life safe and comfortable.

Whereas, emotional acceptance and management means recognizing that Sumi is slowly changing in front of me. And that sooner or later it becomes incumbent upon me to change as well.

For the PWD, a larger area under the Care Partnering Strategies Curve is better as it shows a greater knowledge and understanding of the disease. But a smaller area under the Emotional Curve is better as it shows successful emotional management and problem-solving skills. These two aspects combined is an indicator of becoming an effective care partner.

Thank you