

The Grieving Process

Our Alzheimer's Journey

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November 10, 2021

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 professional care and love, Sumi's Journey would be much different.

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Terms to Know

A **Person With the Disease**, or **PWD**, is someone like my wife, Sumi, who has Alzheimer's disease.

A **Care Partner** is someone like me who is taking care of his/her spouse a **PWD**.

01

Introduction

MY JOURNEY WITH SUMI



- 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. Little caregiving.
- I hoped for a misdiagnosis. Then got educated, read all the books I could.
- At first, I wanted to change Sumi's behavior then I realized I needed to change myself by taming my alpha-male tendencies to care for her.
- 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 8 ½ 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, at a lesser height.

MY JOURNEY WITH SUMI

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

1. Increase Awareness of Alzheimer's. Fight stigma
 2. Share my thoughts and feelings. It allows me to channel my feelings, document changes, and share a glimpse into our lives.
 3. Let my writing be a barometer of my health. Stanford Study
- I write "in the moment" to help process my emotions
 - I find it therapeutic
 - From my writing, I develop stand-alone essays
 - Our Alzheimer's Journey – Grieving Process is one of the 25+ essays
 - My essays can be read on my website:
<https://myjourneywithsumi.com>

02

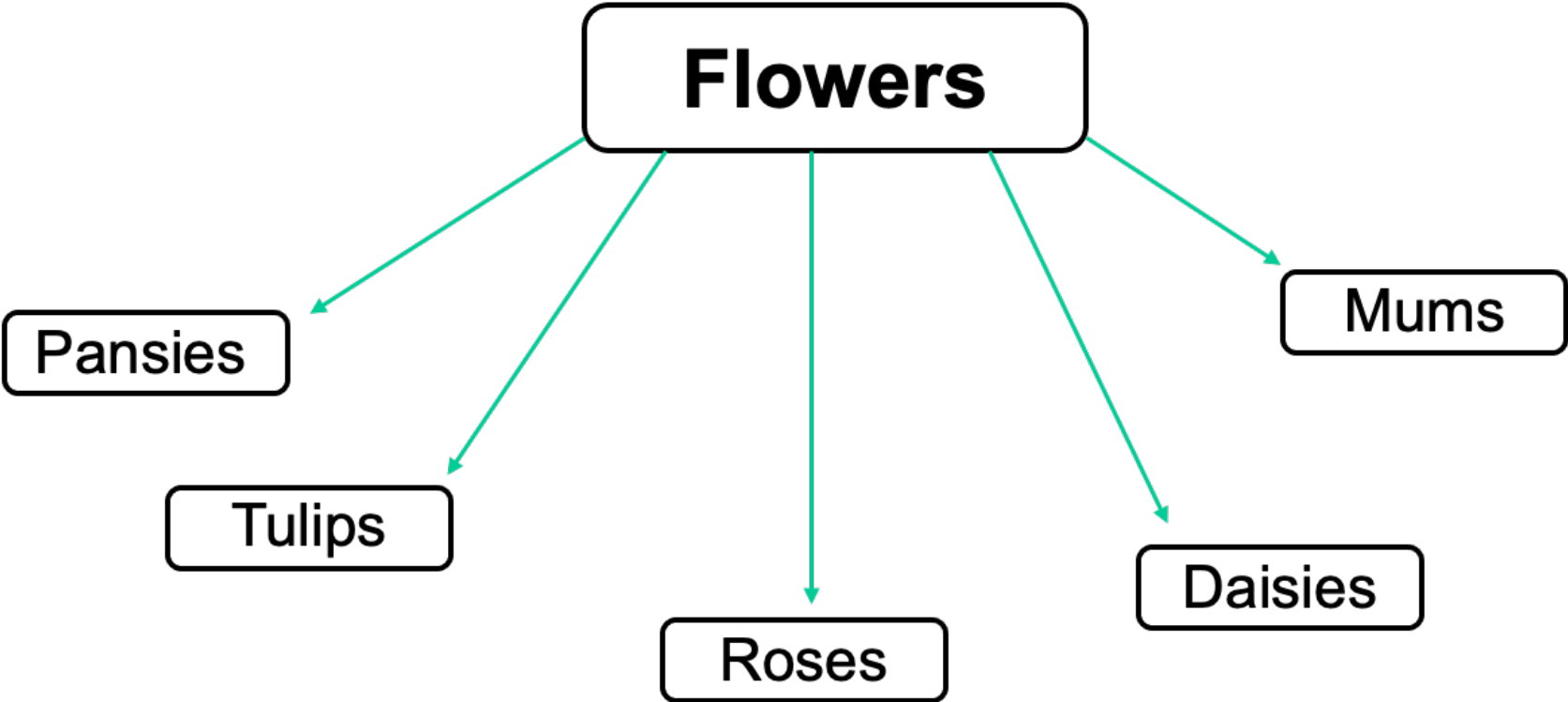
What is Dementia?

Dementia is a serious loss of cognitive functions to perform daily tasks.

It causes changes in:

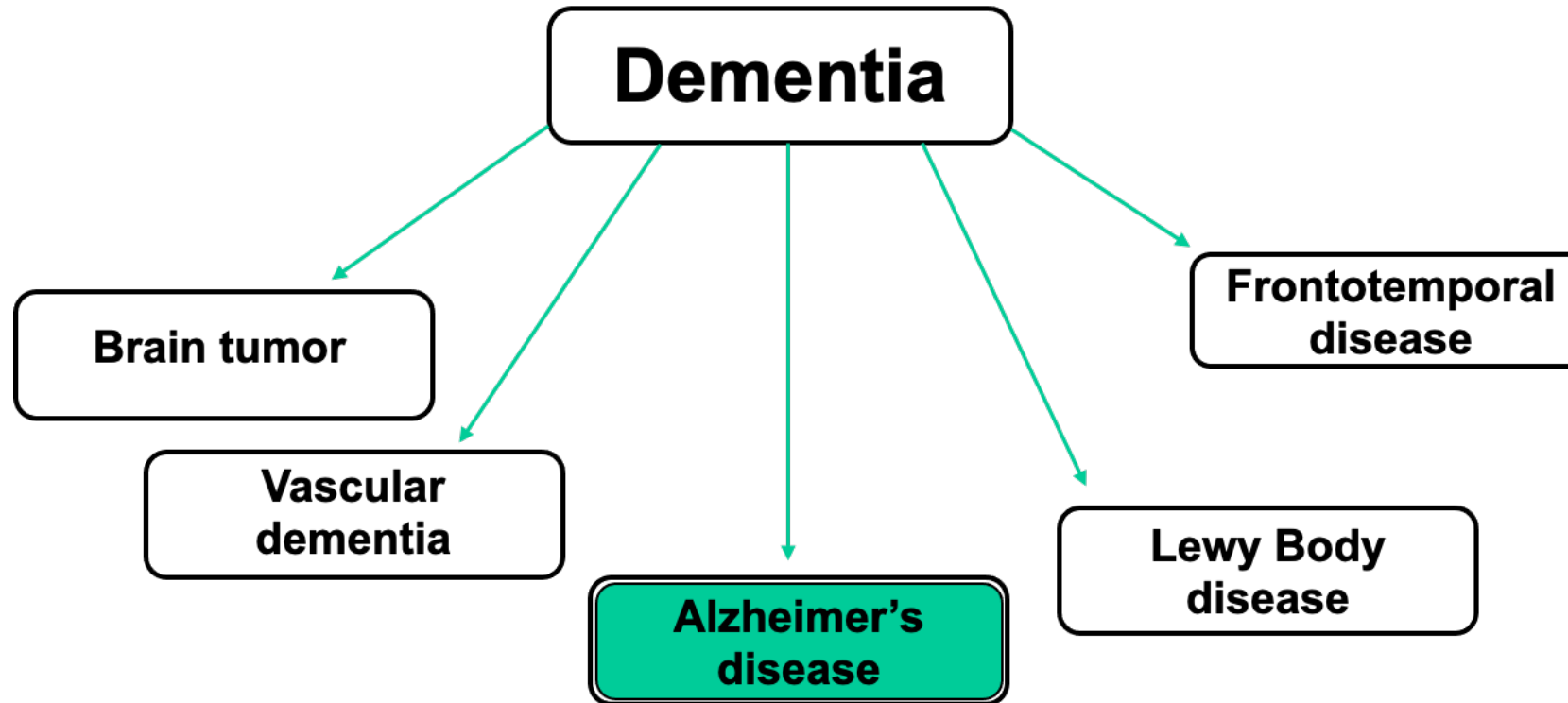
- Memory
- Language
- Executive function (planning, organizing, and attention)
- Visual / spatial skills
- Judgement / reasoning
- Personality / mood

Dementia and Flowers Metaphor*



* Source: Alzheimer's Association

Types of Dementia*



- About 60% of dementia is Alzheimer's⁺
- It is a progressive disease with no cure
- And, eventually, it is fatal

* Source: Alzheimer's Association
+ = ALZHEIMERS.ORG.UK

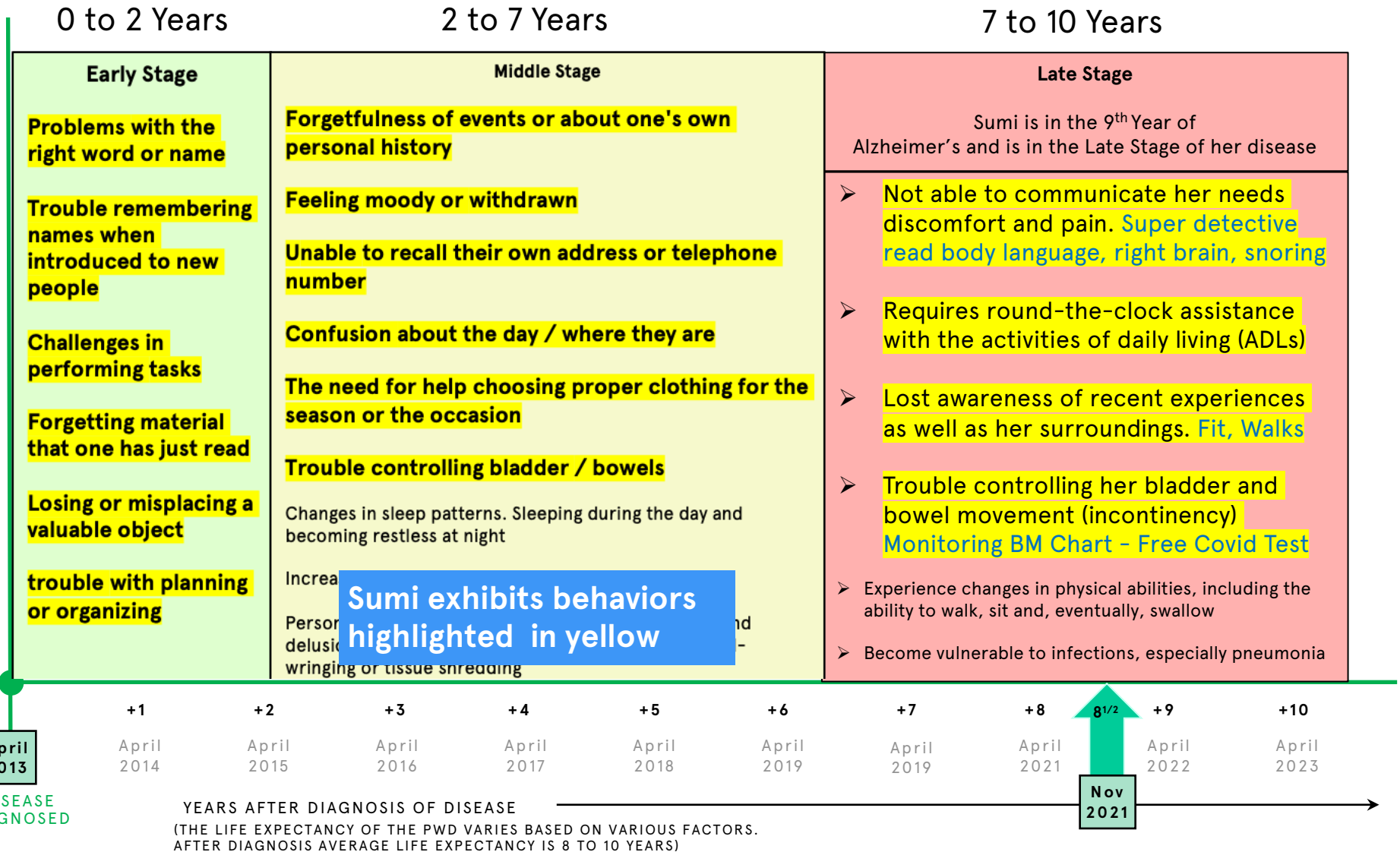
03

3–Stages of Alzheimer's

3-Stages* of Alzheimer's Disease

3-Stages* of Alzheimer's Disease

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

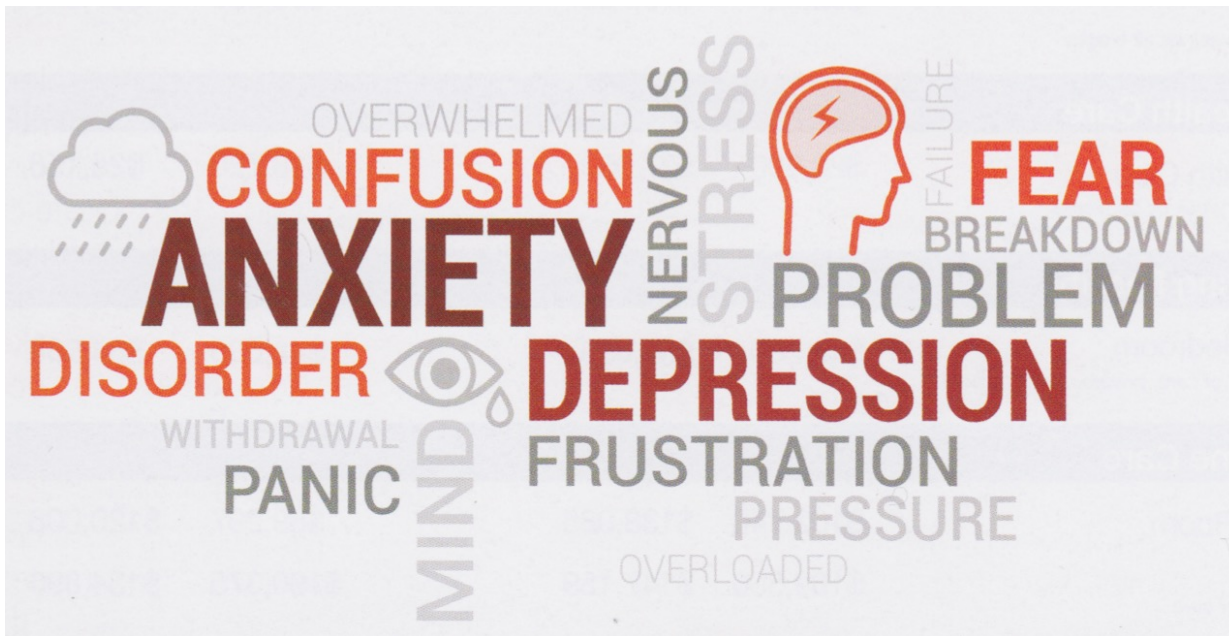


* Source: Alzheimer's Association

04

Emotional Roller-coaster

Our Alzheimer's Journey – Emotional Challenges and Managing Caregiver Stress



5-Stages of Grief (by Elisabeth Kubler Ross):

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

SARA:

- Shock
- Anger
- Reflection
- Acceptance

All this bundle of mixed Emotions were present in us throughout Our Journey

I will un-bundle these emotions showing how I have been riding this emotional roller-coaster

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

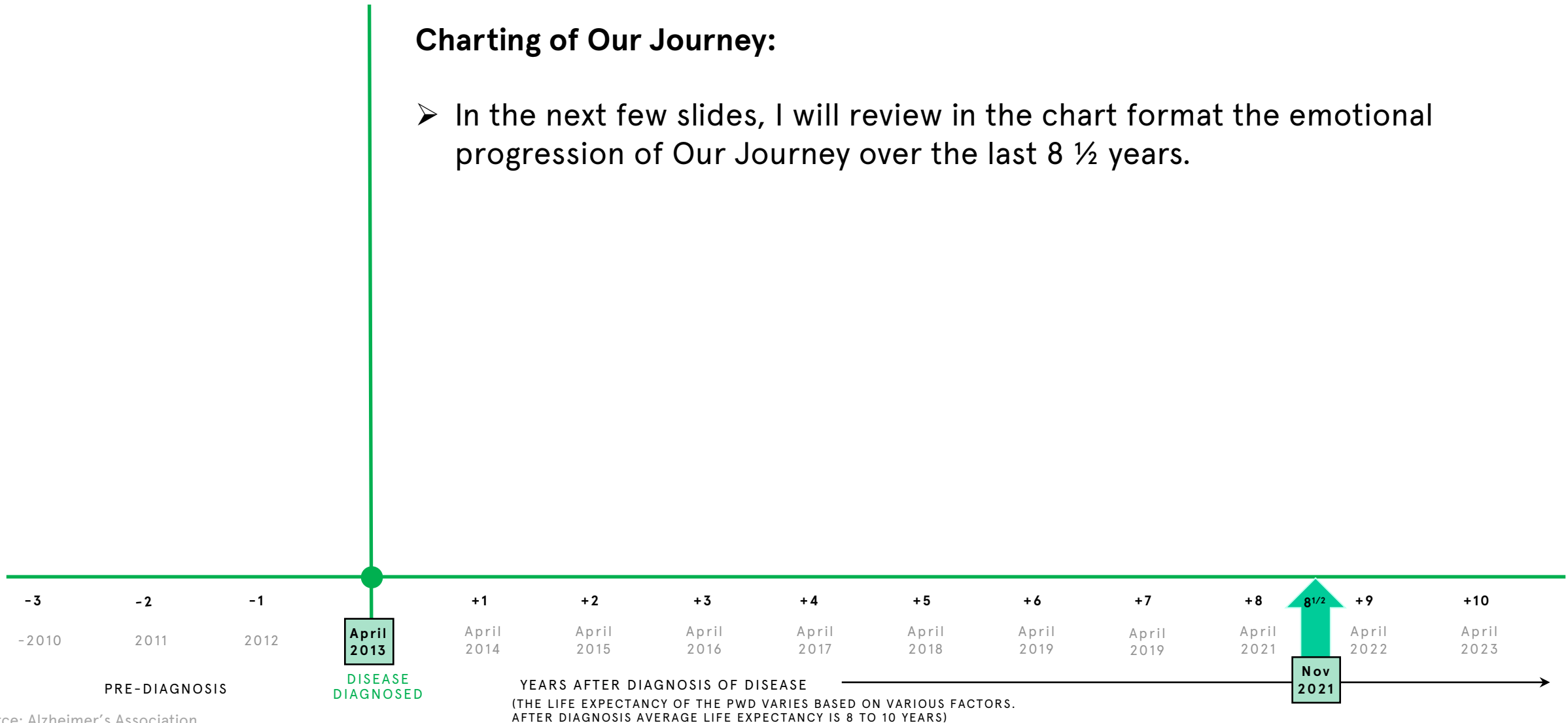
05

Charting of Our Alzheimer's Journey

Our Alzheimer's Journey – Charting of Our Journey

Charting of Our Journey:

- In the next few slides, I will review in the chart format the emotional progression of Our Journey over the last 8 ½ years.



* Source: Alzheimer's Association

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

Our Alzheimer's Journey – Average Life Expectancy

Pre-Diagnosis Phase:

➤ Green vertical line is the time of Sumi's diagnosis (Apr 2013)

- There are usually 1 to 3 years, or more, of symptoms present before the diagnosis.
- I have included those years on the left as Pre-Diagnosis Phase.
- Trigger Point

Post Diagnosis Phase:

- The average life expectancy is 8 to 10 years. However, in some cases it can be as short as 3 years or as long as 20 depending on various factors** such as:
Age at the time of diagnosis, gender, other health problems, severity of symptoms and brain abnormalities.
- For the illustrative purpose, I have chosen a 10-year life expectancy
- Each Person with the Disease (PWD) and their care partner have unique circumstances. Their journey could be totally different from ours.
- However, there are many general paths that most PWDs and their care partners will travel. All these paths can be depicted in many ways. There are no hard and fast rules. What fits one situation may not fit others.
- What I am going to review is Our Journey... What happened to us.



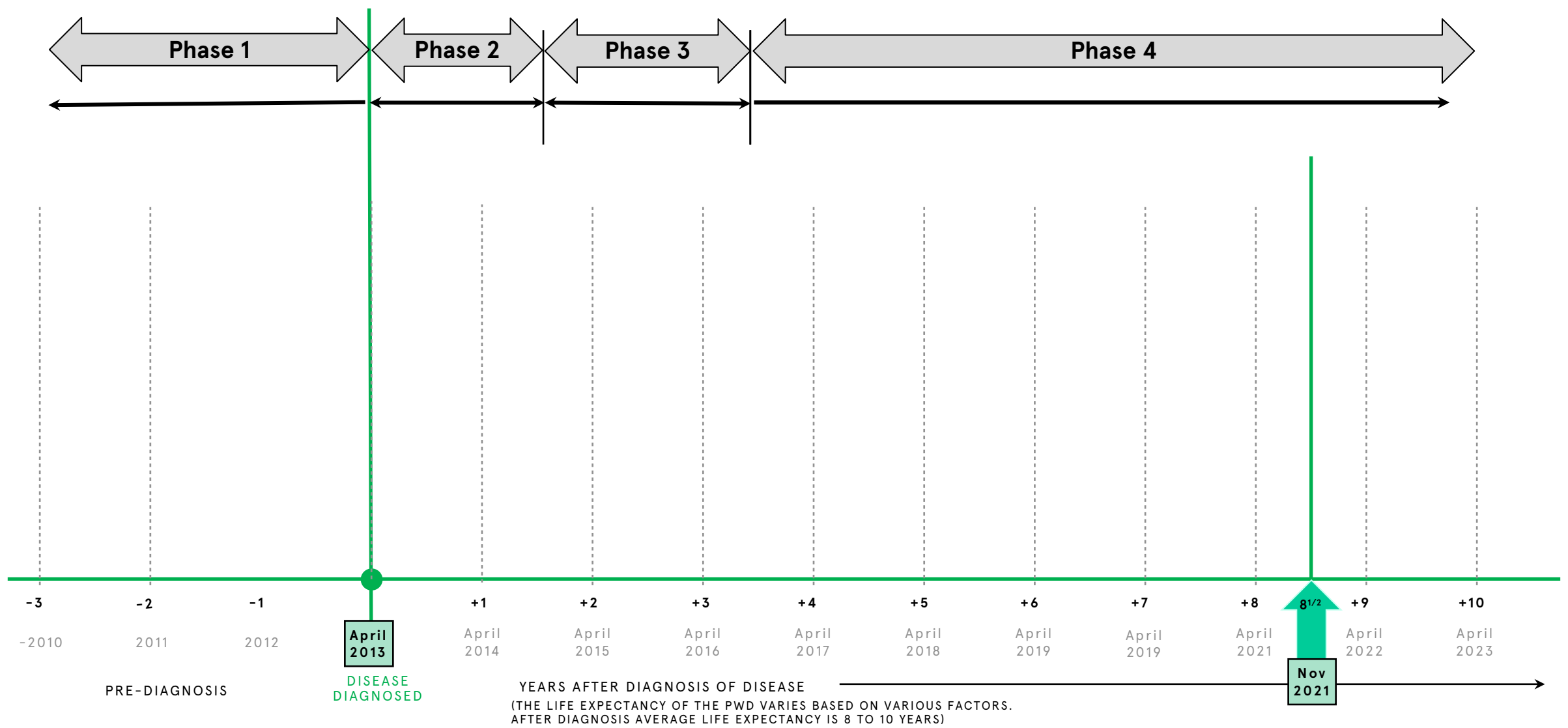
YEARS AFTER DIAGNOSIS OF DISEASE
(THE LIFE EXPECTANCY OF THE PWD VARIES BASED ON VARIOUS FACTORS.
AFTER DIAGNOSIS AVERAGE LIFE EXPECTANCY IS 8 TO 10 YEARS)

* Source: Alzheimer's Association

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

Our Alzheimer's Journey – The Grieving Process

Curve with Emotional Acceptance and Management with Frequent "Emotional Spikes"



* Source: Elisabeth Kubler Ross

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Emotional Curve – Grieving Process and Reconciliation

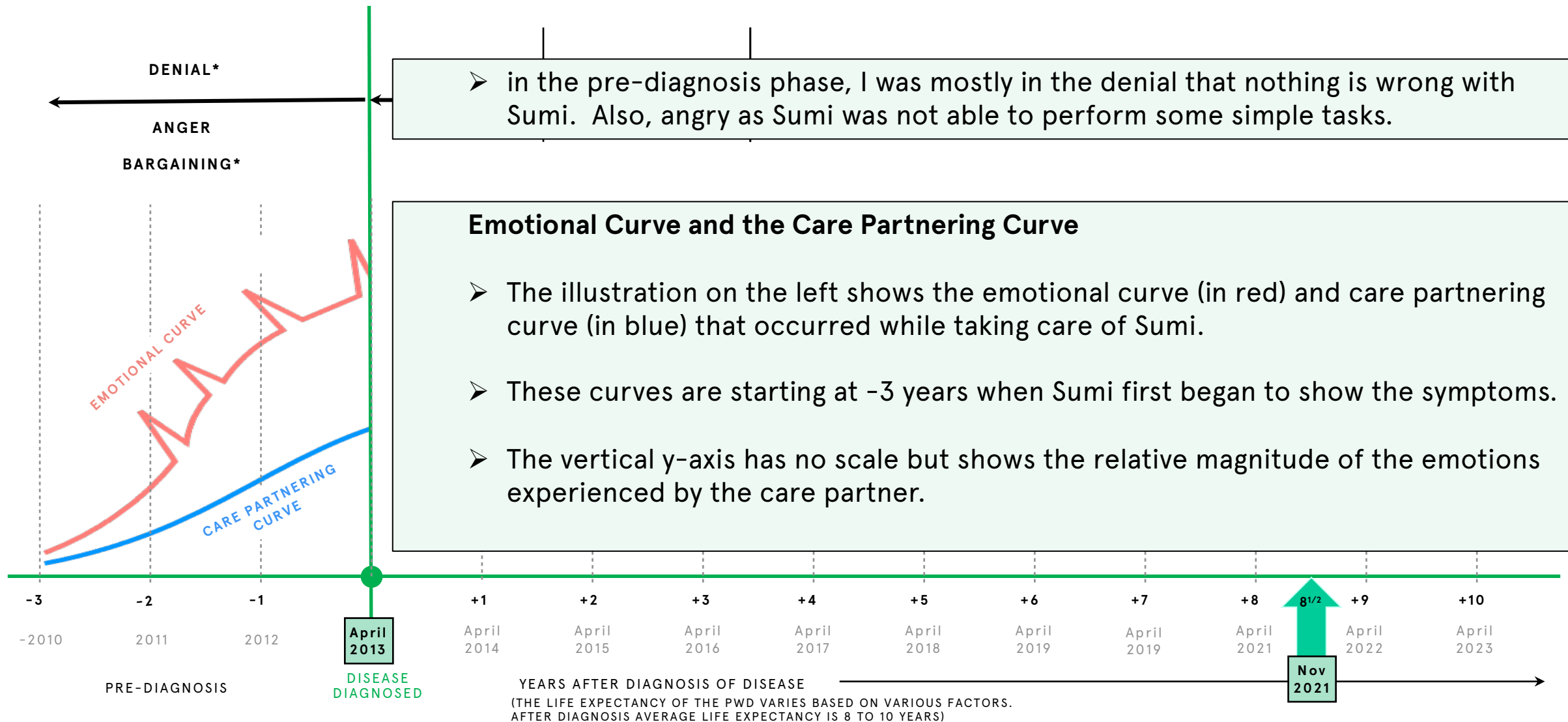
Our Alzheimer's Journey – The Grieving Process

Emotional Curve with Frequent “Emotional Spikes”

- **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, became unidirectional and non-reciprocal.**
- **My love for Sumi became 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 could take over.**

Our Alzheimer's Journey – The Grieving Process

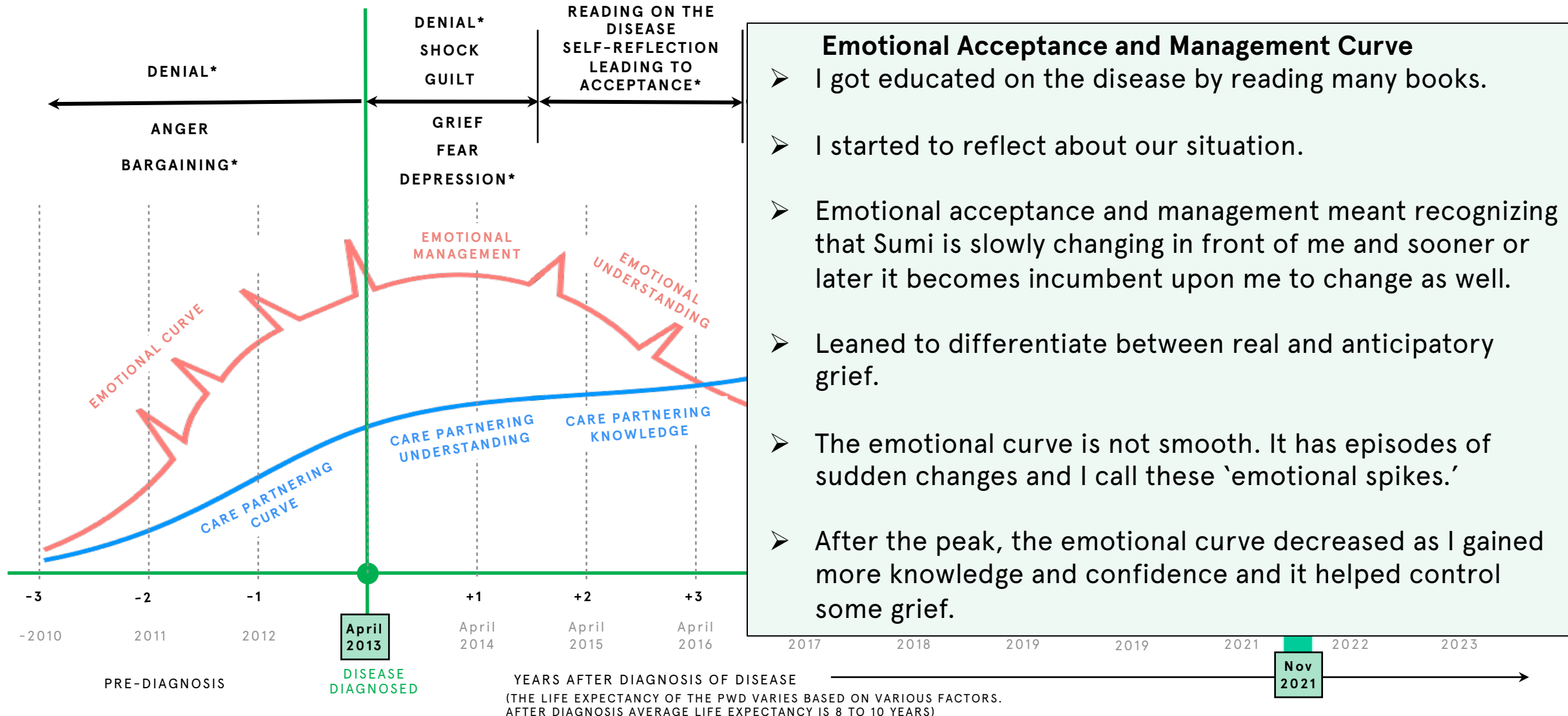
Emotional Curve with Frequent "Emotional Spikes"



* Source: Elisabeth Kubler Ross

Our Alzheimer's Journey – The Grieving Process

Curve with Emotional Acceptance and Management with Frequent "Emotional Spikes"

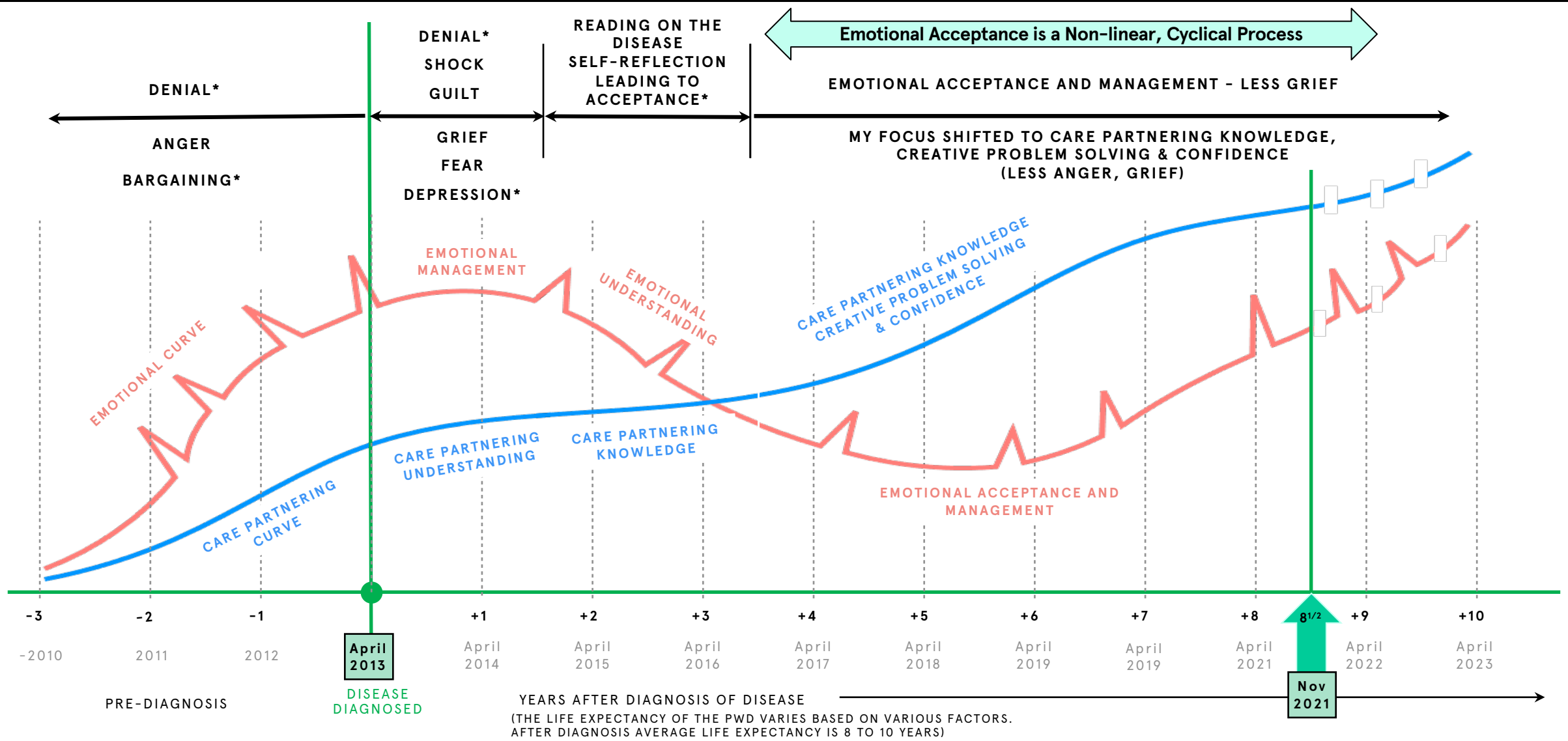


YEARS AFTER DIAGNOSIS OF DISEASE
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Our Alzheimer's Journey – The Grieving Process

Curve with Emotional Acceptance and Management with Frequent "Emotional Spikes"



* Source: Elisabeth Kubler Ross

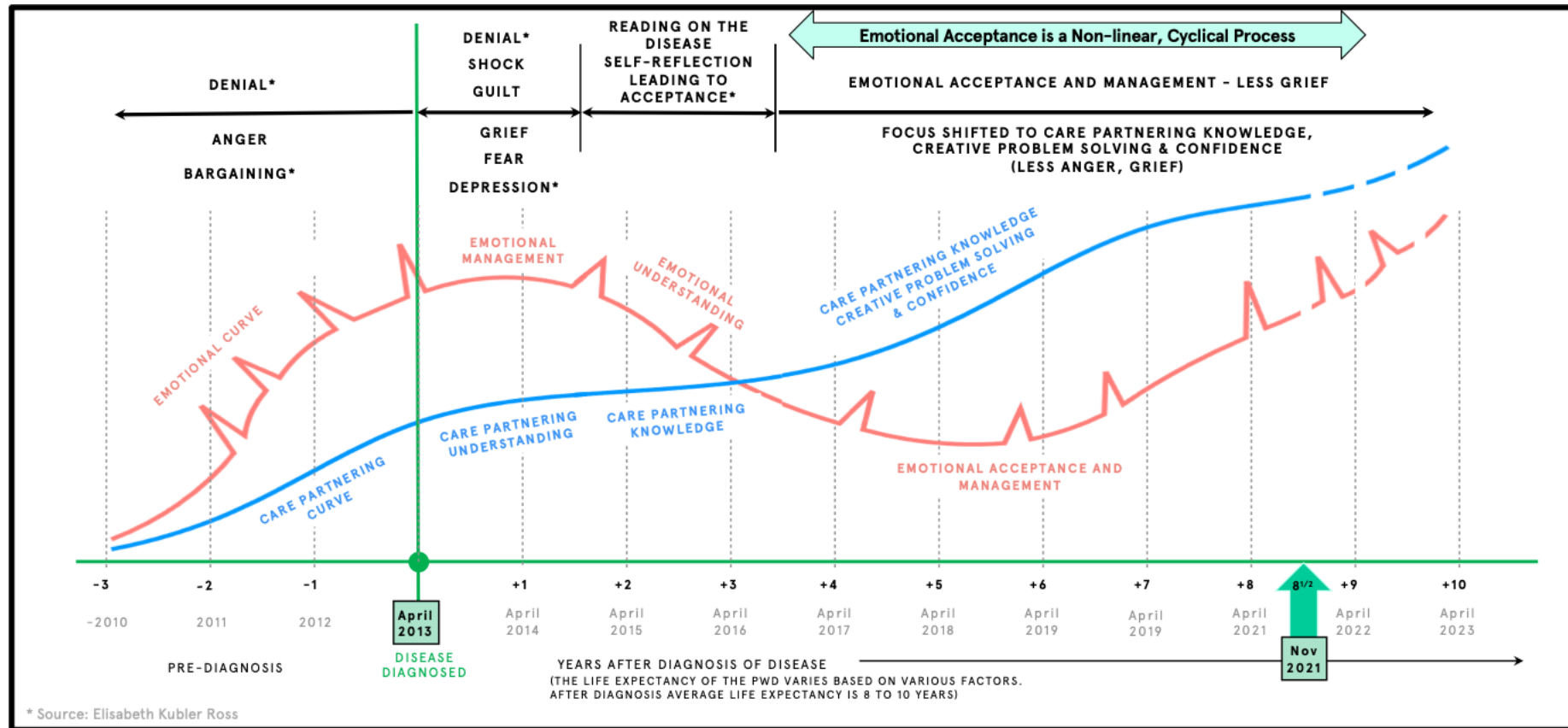
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A Curve of Care Partnering Knowledge Creative Problem Solving and Confidence

Our Alzheimer's Journey – The Grieving Process

1/6 – Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence

1 of 6



Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence

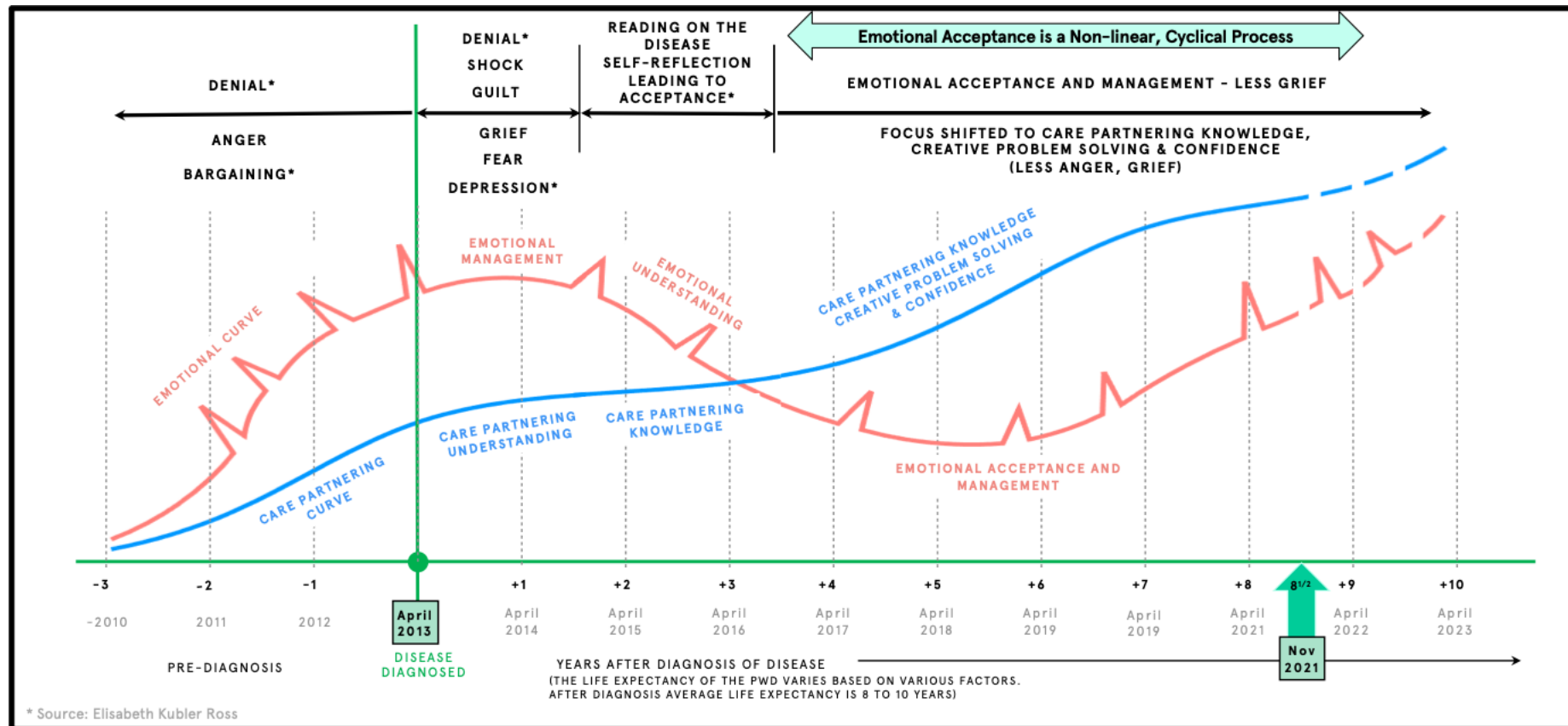
- This ranged from: arranging for caregivers to take care of Sumi's daily chores like toileting, bathing, dressing, feeding etc.
- It also included taking care of the legal, financial, and medical matters.

* Source: Elisabeth Kubler Ross

Our Alzheimer's Journey – The Grieving Process

2/6 – Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence

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Some of my creative problem solutions were:

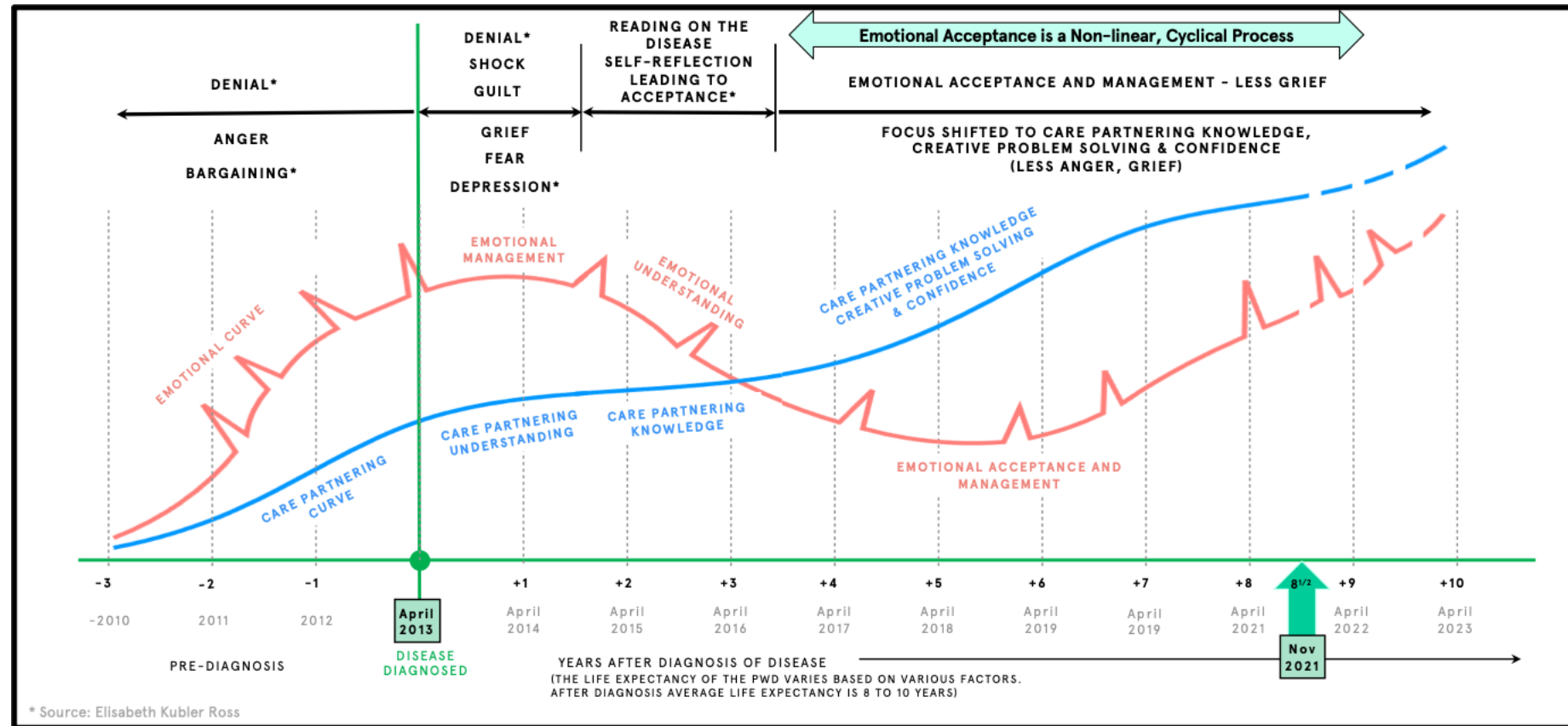
- Installing cameras in the house to monitor Sumi's movements.
- Installing a motion sensor alarm in the bedroom so when Sumi tries to get out of bed I am alerted or awoken to tend to her needs.

* Source: Elisabeth Kubler Ross

Our Alzheimer's Journey – The Grieving Process

3/6 – Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence

3 of 6



More Creative Problem Solving Examples:

- 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 reduces my anger and frustrations.
- Putting soft foam pads on any surfaces Sumi could bump in to.

* Source: Elisabeth Kubler Ross

Our Alzheimer's Journey – The Grieving Process

4/6 – Care Partnering Knowledge, Strategies, Creative Problem Solving and Confidence

4 of 6



1 Garage to house ramp



2 Anti-skid (Dycem) mat for the dinner plate



Before



3 Shower knob

After



4" PVC Coupling over the shower knob



4 Ramp from the foyer to the sunken family room

More Creative Problem Solving Examples:

1 Building a ramp from the garage to the house..

2 Anti-skid (Dycem) mat for dinner the plate.

3 Rigging up a shroud to go over the shower temperature knobs to prevent accidentally getting cold or scalding water while showering Sumi.

4 Building a ramp from the hardwood foyer to the sunken family room.

Open shower stall (no doors) for ease of showering Sumi



5A



5B



5C

360° Seat Rotation and Sliding Shower Chair with Padded Back, Arms and Seat Belt

- Platinum Shower Seat with 360° Seat Rotation and 20" Travel

As Sumi's disease progresses, falls resulting in serious injuries are inevitable. As a safeguard, sometimes we put wearable safety gears on Sumi:

- A foam padded cap worn by the Lacrosse goalies, and
- A hip protector a foam padded wrap-around worn by the motor cyclists

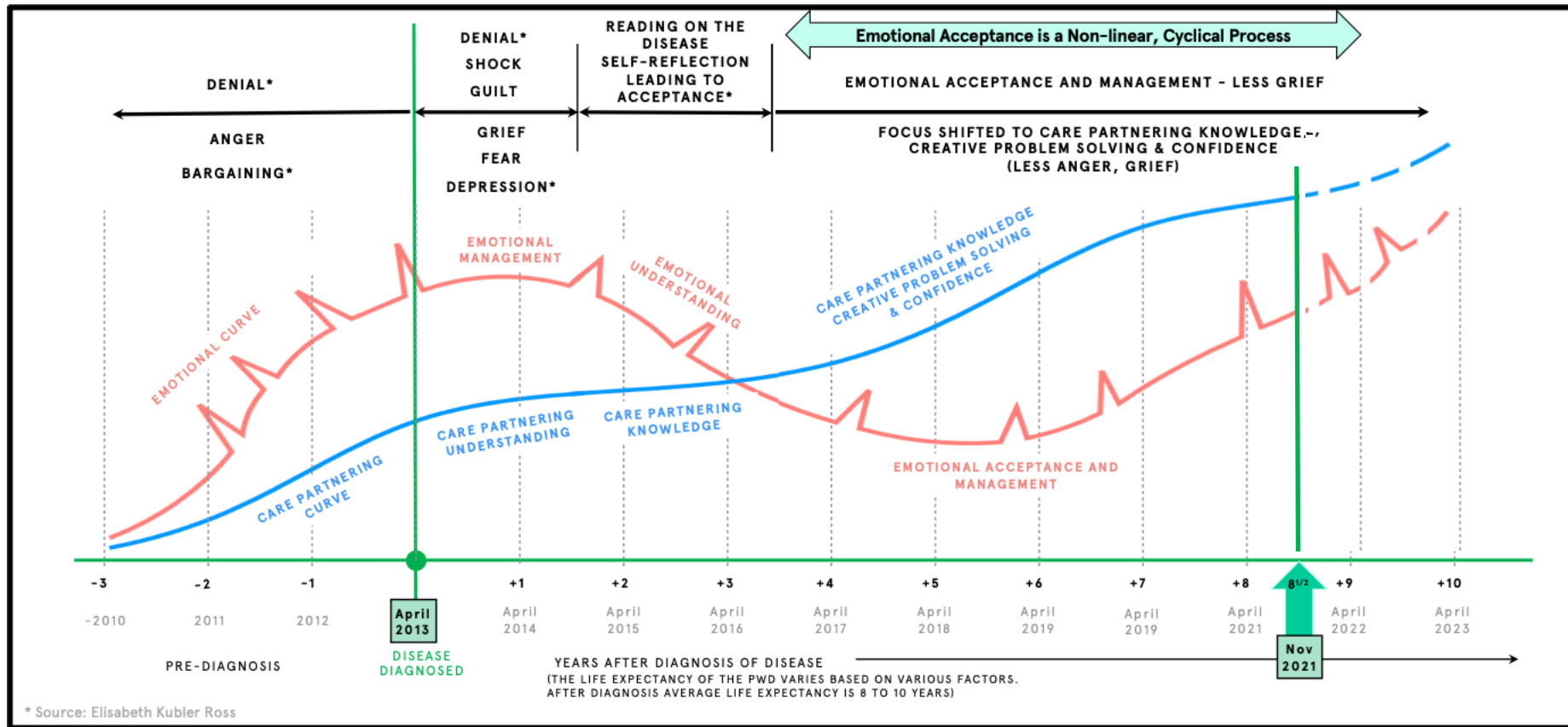
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- This problem-solving aspect of being a care partner gives me small victories. As I test my solutions, it creates a safer and more comfortable environment for Sumi
- I consider my problem solving efforts and rigging up items for Sumi's wellbeing a form of self-care as it temporarily takes my mind away from the caregiving chores

Our Alzheimer's Journey – The Grieving Process

Unknown Future



Unknown Future!

- In the final stage, the brain's functions could 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 the PWD and care partners as the ultimate demise of the PWD becomes a reality.
- Knowing all this, I could be prepared but I know that "one is never prepared for this tragic moment"
- Sad reality - Alzheimer's always wins!

* Source: Elisabeth Kubler Ross

08

Closing Thoughts

I consider myself fortunate that I am in good physical, mental, emotional and financial state that I, and Sumi's caregivers, can provide one-on-one, person centered care to Sumi in our home.

The hardest part of the caregiving is that it is a lonely journey in spite of getting tremendous support from family and friends. It can feel that all dreams and hopes are on pause.

Sometimes, I feel as though I am on a cliff's edge. But with steadfastness, 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.

Changes in Sumi have precipitated changes in me and opened up new internal vistas. Sumi gives purpose, clarity, and focus to my life. I strive to become a better person and husband by being more loving, caring, compassionate, and patient by maintaining emotional equanimity and mindfulness.

I am able to recognize the important things and let go of the trivial. I try to control the controllable and manage the uncontrollable. My anxiety, stress, and the blood pressure have been reduced thereby improving my well-being. I find that I am compassionate, self-healed, little wiser, and at peace with myself.

My Two Sumi's and Two Worlds

- **Before the disease = My First Sumi or, Sumi 1.0**
- **After the disease = My Second Sumi or, Sumi 2.0**

Living in the two worlds of the same person – Sumi 1.0 and Sumi 2.0 – is extremely painful. The reality is that both these worlds co-exist simultaneously, like two banks of the same river. Sumi 1.0 and Sumi 2.0 on each bank.

I can't lock up the former world, the world with My First Sumi, in the deep recesses of my mind and forget about it. At the same time, I can't ignore the current and real world with My Second Sumi.

After a long struggle, I have figured out my well-being depends on smoothly navigating between these two worlds with a balanced mind and not getting overwhelmed by either of them.

It is like crossing a rickety suspension bridge over a turbulent river when I'm not even sure I want to get to the other side to visit Sumi 1.0. But with a determined resolve, I *do* cross it and navigate between the two banks of the river all while maintaining my equanimity!

My Two Sumi's and Two Worlds

The common thread in my two worlds is Sumi's smile.
Every day I try hard not to let that go!

Sumi 1.0
1974

(2 weeks
after our
marriage)



Sumi 2.0
Now

(47 years
later)



In our Journey, I have realized that Grief is not the process of forgetting, or suppressing the memories of Sumi in the deep recesses of my mind, but

Remembering those memories, at will, or on special occasions, with less pain.

Thank you