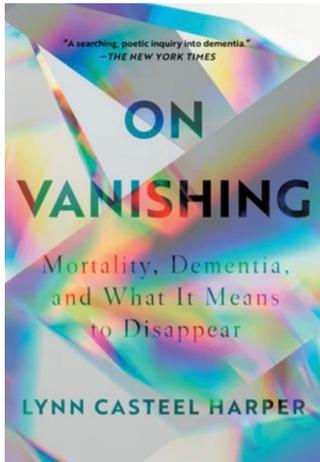


# On the Path of the Perfecting Caregiver

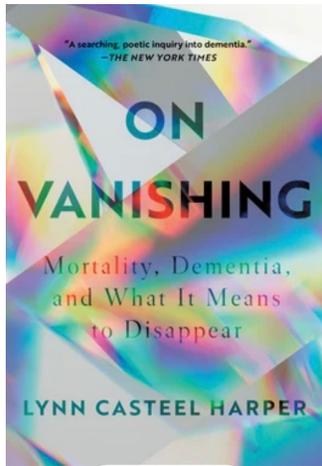
*On Vanishing*  
Reflections and Connections

Current Update: 02/24/2026

Ernest L. Pancsofar



***This book had been recommended from several people, whose wisdom I hold in high regard. I focused on aspects of the book that had direct application to my role as caregiver for my wife, Marsha, as she lived her later years with dementia. Reading this book allowed me to reflect on entries to my journal and previous documents I have included at [pancsofarblog.org](http://pancsofarblog.org).***



Emers **O** n's

**F**i **N** al Days

Being **V**ulnerable

Complement **A** ry Nature of

Dark **N** ess and

**L** / **g**ht

Gift **S** Offered

**W** **H** en I Get

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The Golde **N** Hour

**G** entleness

Spiritua **L** ity

Ambiguit **Y**

Perso **N** hood

Empowerme **N** t

So **C** iety's

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Wi **S** dom

**T** ransforming Our

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**G** **R** ounds For

Scul **P** ture

Se **E** ming To

Mis **R** ecognition

## Emerson's Final days

In my early youth growing up in New England, I was an avid reader of the works of Emerson and Thoreau.

During this time, I never read about Emerson's final years as his verbal skills and cognitive abilities declined.

He demonstrated that one can live with grace and dignity if supported by caring friends and loved ones.

Each of us will experience a different final chapter to our lives as we continue to experience the reciprocal interchanges of feelings and emotions among those who witness our life at that time.

## Being Vulnerable

Coming face-to-face with the death of a loved one creates a sense of my own vulnerability with facing my inevitable, future passing. I feel less frightened by my own vanishing and look forward to the transformation that will occur. I am reminded of the lyrics to *Let the Mystery Be* by Iris DeMent. I have lived a fulfilled and contented life. I share my thoughts and feelings with Marsha's end of life experience via prose, poetry and graphic organizers. The uncertainty of what will happen tomorrow influences the choices I make today. I am open to new possibilities with a freedom of exploration that is strengthened by my caregiving roles and responsibilities.

# Complement A ry Dark N ess and L I ght

I had developed an initial visual organizer on two opposing outlooks on dementia using light versus shadow. After reading Lynn Casteel Harper’s treatment of how using light/dark comparison results in an either/or rather than a complementary view of light and darkness, I developed a revised graphic below.

## Acrostic Visual Organizers

Shadow Side		In the Light
What Do You Need	<b>D</b>	Develop Interdependence
A Lost Adventur	<b>E</b>	Enrichment of “What Is”
Doom & Gloo	<b>M</b>	Meaningful Times Together
Dreadful Fat	<b>E</b>	Enduring Love & Connection
Sadness & Depressio	<b>N</b>	New Sense of “Normal”
Dwell on What is Los	<b>T</b>	Thankful for What Still Is
A Lost You and	<b>I</b>	Welcome a “New “ Us
Missing Parts of Marsh	<b>A</b>	Access to Marsha’s “Essence”

## Focus We Bring to the Caregiving Experience

Loss of Personhood  
Dependency  
Nothing to Offer

Promoting Personhood  
Interdependency  
Cocreate Healthy Relationships

Dependency Expecte **D** evelop Interdependence

A Lost Adventur **E** nrichment of What Is

Doom and Gloo **M** eaningful Times Together

Dreadful Fat **E** nduring Love and Connection

Sadness and Depressio **N** ew Sense of “Normal”

Dwell on What Was Los **T** hankful For What Still Is

A Lost You and **I** Welcome a New “US”

Missing Parts of Marsh **A** ccess to Marsha’s Essence

# Gift S Offered

What are the gifts offered to me via my interactions with Marsha during our experiences together as she lived with dementia?

1. Simplicity
2. Mindfulness
3. Peaceful times together
4. Noticing what nature has to offer as background sounds
5. A chance to try again at supports that may not have been successful the first time around
6. Unconditional love
7. Creative outlets for my journaling
8. Access to peers who were also in caregiving roles with a loved one
9. Reflection of our lives together
10. Admiration for her courage and a model for my own anticipated end of life experience

***A gift comes to you through no action of your own, free, having moved toward you without your beckoning. It is not a reward; you cannot earn it, or call it to you, or even deserve it. And yet it appears. Your only role is to be open-eyed and present. Gifts exist in a realm of humility and mystery – as with random acts of kindness, we do not know their source. Robin Wall Kimmerer***

## The Golden Hour

Witnessing the time during which darkness evolves into light at the beginning of each day and light transcends into darkness at the end of each day, brings clarity to the in-between times in our days and lives. There can be a moment of awe at the intersection of the 50/50 split that words may fail to adequately describe. This moment may be nature's way of telling us to prepare for our own transitions/vanishings when we change/transform into our natural progression of being. As Marsha's breathing ended with one final exhale, I was privileged to witness a passing of her spirit from her body to the beyond. I would identify this as a "golden" moment. I don't exactly know for certain what occurs next, but I hold the anticipation of a mystery that will unfold in its due course for me.

## When I Get Demented!

At the time of this writing, my dad is currently 108 years-old and my mom is 101. If longevity is in my genes, there is a strong possibility that I will experience a cognitive decline as I approach those milestones. My positive outlook for doing so is enhanced by my current knowledge of the supports that need to be in place for one to "enjoy" this time with a focus on relationships and interactions with loved ones and a focus on the here-and-now. Being in each other's presence and bearing witness to the essence of what each person brings to a relationship relies little on cognitive abilities but more on sensory and empathic orientations.

# G entleness

As a member of a speaker's bureau among peers affiliated with LiveWell in Connecticut. I have composed a sequence of questions/phases within a challenge I would encounter in my caregiving role with Marsha. I would search for the gentlest response after pausing to process the challenge and my interpretation of the "real" message contained within each challenge. The questions I ask are located on the following page followed by an experience that I share from my perspective as a caregiver.

**I am adopting a new format to a previous edition of Lessons Learned by framing each lesson in the following four questions:**

**E =** What is the **Experience**?

**P =** **Pause/Process** - what is the essence of what is happening?

**R =** How can I **respond** in the gentlest manner taking the processing step into account?

**R =** What brief **reflection** can summarize my learning?

Each **experience** on the following pages is an event that occurred spontaneously between Marsha and me that presented a challenge for how I should/could best respond.

As each experience unfolded, I **paused**, built in a "wait time" to understand what was going on, and **processed** what approaches to try next in my role as caregiver.

When I did **respond**, I wanted my reaction to be the gentlest way I could enter into the challenge given my past experiences and current feeling of what to do.

Finally, after I captured the learning moment in my daily journaling practice, I developed a very brief **reflection**; not always right away.

# G entleness

(continued)

## Experience

After arriving back home from a brief trip in the car, Marsha told me she was not going in the house.

## Pause/Process

I decided this was not an emergency and tugging on her or using loud words were not in order. I went in the house and invited her to join me. After five minutes with no movement, I went back out and sat in the driver's seat and told her I would wait for her to go in the house. After 5 minutes, I got out and invited her to join me in the house.

After another 5 minutes elapsed ...

## Respond

I poured a drink of juice, went out to the car and gave it to Marsha with the words, "Bring this glass back in the house when you're through," and I went back into the house. About 5 minutes later, I noticed Marsha getting out of the car and heading into the house. Success!

## Reflection

There's more than one way.

# Spiritua L ity

I reviewed previous writings and quotes to bring to the surface some definitions and context about what spirituality means in my life.

*Spirituality is not a formula; it is not a test. It is a relationship. Spirituality is not about competency; it is about intimacy. Spirituality is not about perfection; it is about connection. The way of the spiritual life begins where we are now in the mess of our lives. Mike Yaconelli*

## **First Nations Blessing**

*Now you will feel no rain,  
For each of you will be shelter to the other.  
Now you will feel no cold,  
For each of you will be warmth to the other.*

**Poster text is the Golden Rule as it appears in 8 religions.**

I was attending a *Courage to Teach* workshop many years ago and I noticed a poster on the wall of one of the meeting rooms. On the poster were tenets of several religions, all of which contained some variation of the golden rule. It appeared that the starting frame of reference for many can lead to this equivalent way of being.

**Christianity:** Do unto others as you would have them do unto you.

**Judaism:** What is hateful to you do not do to your neighbor. That is the entire Torah. The rest is commentary. Go and learn.

**Islam:** No one is a believer until you desire for another that which you desire for yourself.

**Baha'i:** Blessed are those who prefer others before themselves.

**Zoroastrianism:** Human nature is good only when it does not do unto another whatever is not good for its own self.

**Sikhism:** Be not estranged from one another for God dwells in every heart.

**Jainism:** In happiness and suffering/in joy and grief/regard all creatures as you would your own self.

**Buddhism:** Hurt not others in ways that you yourself would find harmful.

# Ambiguity

*Perhaps, persons with dementia call us to confront our own ambiguity, to realize just how difficult it is to pin down one's own identity, let alone someone else's.*

**Lynn Casteel Harper, *On Vanishing***

Below are two quotes that resonate with me when I think of the term ambiguity.

*I wanted a perfect ending. Now I've learned, the hard way, that some poems don't rhyme, and some stories don't have a clear beginning, middle, and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next.*

**Gilda Radner *Delicious Ambiguity***

*Research shows that we do better to live with grief than to deny it or close the door on it. Our task now, after a time of so much suffering, is to acknowledge our losses, name them, find meaning in them, and let go of the quest for closure. Instead of searching for closure, we search for meaning and new hope. We begin this search by becoming aware of family losses even from years ago.*

**Pauline Boss, *The Myth of Closure: Ambiguous Loss in a Time of Pandemic and Change***

## Perso N hood

I strongly believe that my concept of personhood has evolved from my early experiences with individuals with severe and profound cognitive impairments and has remained so to this day. The ability to “think” or communicate one’s intention is not the defining characteristic of personhood. I will go to the extreme of being in the presence of an individual in a comatose state. That individual has personhood. Perhaps the basic act of breathing and being conceived and born into this world is the sole criteria of personhood. I was taught to be a gentle, caring presence in the interactions I had with students in my first teaching experiences. My personal values formed within that setting. It is no coincidence that a fellow teacher who worked down the hallway with young children with both physical and cognitive disabilities would be my future wife. You learn about a person’s character when you witness them interact with students with complex medical and educational needs. I carried those values with me as the primary caregiver when Marsha lived the final five years of her life with Alzheimer’s disease. Her “personhood” was not diminished by her decreasing capacities to think, communicate or care for her physical needs. I viewed her as my equal to her dying breath.

# Empowerment

In 2021, I wrote my point of view on the topic of empowerment as I anticipated how it would play a role in my upcoming retirement.

## **As written in 2021**

I have strength and ability to act  
On my own behalf. In fact  
My life's goals have been achieved.  
Now it's icing on the cake and I'm relieved  
To be satisfied with my wants and needs  
And perhaps I have planted some seeds  
For others to continue to hoe  
For whatever ends. I know  
My life has had meaning  
For I am still achieving  
What matters most:  
An inner sense of peace as I post  
My notes for whomever to read;  
The values and truths I have believed.

I rethought the concept of empowerment from Marsha's perspective during the later days of living with significant cognitive decline.

## **Added in 2025**

I need to give you more choices during the day.  
This is your home and you should have a say  
In where you want to go and wander.  
I'll be your guide on our daily saunter.  
I feel empowered to tell our story  
Of the ins and outs of our current journey.  
Help me learn to understand your point of view.  
Help me listen to what you want to do.  
Sometimes it's hard to know your intentions.  
I will listen more intently to your facial expressions.  
We are not in any hurry; we live at a slower pace.  
You enhance our lives with your enduring grace.  
You whisper more than you talk out loud.  
You squeeze my hand and you make me proud  
To be your companion and best friend forever  
In each and every family endeavor.

# So C iety's Expect A tions

There appears to be a psychological defense at work that increases the likelihood that many citizens will choose not to carry on a relationship with a current friend once a diagnosis of dementia is given to that friend. Perhaps a key reason rests in society's refusal to acknowledge that each of us can delay our own "coming to terms" with our own finality if we stay away from those whose final days are more imminent.

***I don't measure myself by others' expectations or let others define my worth. Sonia Sotomayor***

***I was looking for myself and asking everyone except myself questions which I, and only I, could answer. It took me a long time and much painful boomeranging of my expectations to achieve a realization everyone else appears to have been born with: That I am nobody but myself. — Ralph Ellison, Invisible Man***

***Welcome to Expectations ...  
... the whether man - There are no wrong roads to anywhere.  
... expectations is the place you must always go to before you get to where you're going. Of course, some people never go beyond expectations ...***

Norton Juster, *The Phantom Tollbooth*

Also, one's worth is often directly associated with the "current" contribution each citizen is making to the overall productivity of society. In retirement, our elderly are often not included in the conversation of "what's best for the national good." The elderly are often marginalized to the fringes of society's allotment of funds for living a more fulfilled life "on the backs" of the currently employed.

# Wisdom

Below are some snippets from my journaling on the topic of “wisdom.”  
These are my statements unless otherwise noted.

**Realizations of the Past** cause me to wonder  
About the wisdom we find in our younger  
Days that is refined upon further reflection  
In our days of current inspection.

**W**rite reflections

**I**nvolve loved one in choices

**S**hare experiences with family members

**D**iscover creative approaches

**O**bserve contented involvement

**M**ake mistakes – learn from

*I don't think you can come  
into your wisdom until you  
have made mistakes on  
your own skin and felt them  
in reality of your own life.*

**Elizabeth Gilbert**

*... dementia does not destroy everything. Often  
something remains that is still wonderful. Out of the fog  
comes surprising wisdom. Pauline Boss*

*My inner voice speaks –  
No one hears but me.  
Wisdom and guidance  
Are offered for free.*

**Age brings wisdom from the telling of my stories.  
Age allows for quiet times for my own inventories.**

*In the past few years I have read and listened to people  
discuss the importance of knowing what to do with the  
information that is available – the act of wisdom.*

# T ransforming Our Liv E s

*The path I choose through the maze makes me what I am. I am not only a thing, but also a way of being--one of many ways--and knowing the paths I have followed and the ones left to take will help me understand what I am becoming.* Daniel Keyes

*We never know how much longer we will live Or how much more to our projects we'll give. It's not the completion of our work that gives meaning, It's how that work changes our inner core feelings. We are who we are - - - not what we have done. The journey is long, we have only begun!* ELP

*If we are always arriving and departing, it is also true that we are eternally anchored. One's destination is never a place but rather a new way of looking at things.* Henry Miller

*All of us every single year, we're a different person. I don't think we're the same person all our lives.* Steven Spielberg

*Everybody is on a lifelong journey toward trying to live more deeply. There is nobody who can say, "Well, I've got that one checked off my to-do list." We have to be honest with ourselves about where we are on this journey and about the difficulty of living in our own identities and integrity.*

Parker J. Palmer

Integri T y  
Hea R ts  
Underst A nd

*... The creative care approach invites us to shift away from the temptation to focus so heavily on losses and instead train our eyes and hearts on the strengths that remain.* Anne Basting

*Maybe the journey isn't so much about becoming anything. Maybe it's about un-becoming everything that isn't really you.* Paulo Caelho

*I think I'm constantly in a state of adjustment.* Patti Smith

A N chored  
S trengths

*When you're finished changing, you're finished.* Benjamin Franklin

Dif F erent

*Life is a process of becoming, a combination of states we have to go through. Where people fail is that they wish to elect a state and remain in it. This is a kind of death.* Anaïs Nin

J O urney

P R ocess

M eaning

Ch A nging

Dea T h

Creat I ve

Bec O ming

Adjustme N t

I now understand that nothing totally prepared me for the death of a loved one.

The caring process for my daily journey was different and ever-changing.

My adjustment to becoming a caregiver was anchored in the meaning I attributed to this experience.

I knew I had to be creative in offering supports that honored Marsha's strengths.

Our two hearts met at the crossroads of identity and integrity.

## Ro E thke

I wasn't acquainted with Theodore Roethke's work except an occasional quote here and there. I was particularly interested in the following:

- *A lively understandable spirit  
Once entertained you.  
It will come again.  
Be still.  
Wait.*
- *Time marks us while we are marking time.*
- *I learn by going where I have to go.*
- *I wake to sleep, and take my waking slow.  
I feel my fate in what I cannot fear.  
I learn by going where I have to go.*
- *Life is a perpetual great astonishment.*
- *The darkness has its own light.*
- *Those who are willing to be vulnerable move among  
mysteries.*

# Our Values

Our values are the foundation for our actions. I collected a few quotes from my journaling on this topic.:

**Eternal life** is all a big question to me  
So I'll just let the mystery be  
And let our values be our guide  
Formed from years with you by my side.

*Perhaps our core set of values remain constant over our lifetime, but the truths that compose these values change as we **mature** and gain experiences in our lives. ELP*

*Tim Dartington, who looked after his wife, Anne, and kept her at home during her last years, told me that what happened with his wife 'transformed my whole way of thinking who I was, what I was doing, what my values were. It changed everything, I was a better person for it ...' Nicci Gerrard, The Last Ocean, (p. 117)*

*Realizing what to do next is often determined by a set of values and truths rather than what is right or wrong to do.*

Parker Palmer's values have heavily influenced my teaching career, especially from his book, *The Courage to Teach*, from which this quote originates:

*Good teaching cannot be reduced to technique; good teaching comes from the identity and integrity of the teacher.*

I could easily substitute the words "caregiver/caregiving" for "teacher/teaching."

Palmer continues in another passage:

*By choosing integrity, I become more whole, but wholeness does not mean perfection. It means becoming more real in acknowledging the whole of who I am.*

# Approaching

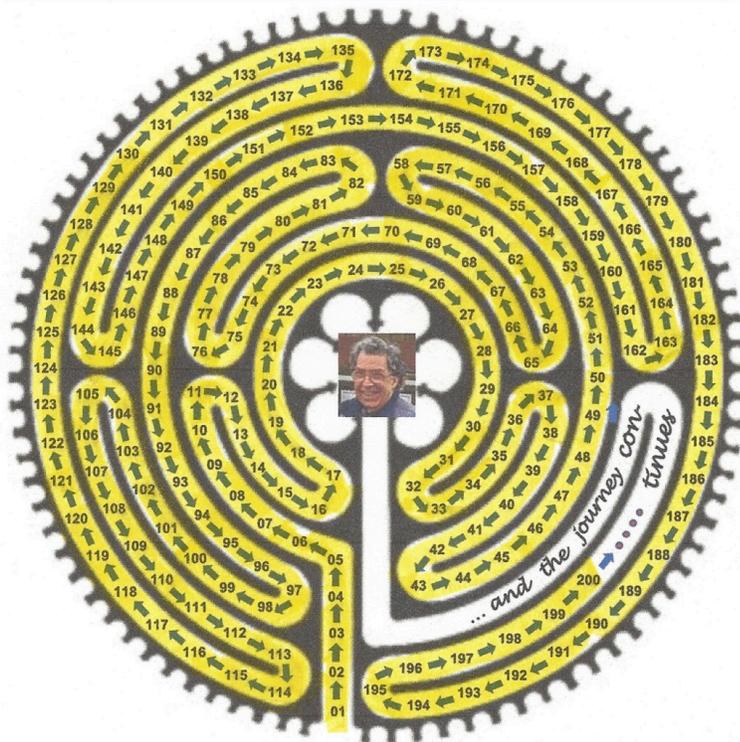
I like the image of “approaching” a goal or another state of being. My choice of words in my journaling is “perfecting.” That is, I am perfecting my teaching or perfecting my caregiving skills. I have never mastered or perfected them.

## On the Path of the Perfecting Teacher

Walking the Labyrinth  
Steps 151 - 200

Current Update: 02/07/26

Ernest L. Pancsofar



# Dre A ms

## To Marsha – “The Dreamer”

The inner workings of the mind  
Produce a dream that's one of a kind.  
No one can tell its meaning and plot  
Except for the one whose mind it sought  
To enter that calm, still night -  
To give the dreamer a clear insight  
Into the workings of the human side  
As she lives her life, it can be a guide  
To figure out what's happened before  
And in her life she can explore  
The mysteries of the recent past  
And make each dream forever last.

ELP – February – 1994

*I learned this, at least, by experiment: that if one advances confidently in the direction of his dreams, and endeavors to live the life which he has imagined, he will meet with a success unexpected in common hours.*

Thoreau

*All people dream, but not equally. Those who dream by night in the dusty recesses of their minds wake in the day to find that it was vanity. But the dreamers of the day are dangerous people, for they may act their dream with open eyes to make it possible. T. E. Lawrence*

11/25/1984

If were to write my American Dream it might be as follows –

*To be able to live each five minutes with no regrets, to have a close network of friends, and a caring thoughtful family. Who could ask for anything more? ELP*

## I've Been Dreaming

The **Dreams** of the young,  
The **Dreams** of the bold,  
For people we support  
Their **Dreams** must be told.

**Dreams** are uncertain.  
**Dreams** can be vague.  
But all **Dreams** are visions  
From Sue, Bob and Peg.

Stop and Reflect.  
Listen with care.  
Give your support  
And your **Dreams** to share.

Today's a good day  
To sit and to listen  
To share and reflect  
To talk and to vision.

A **Dream** will grow.  
A **Dream** will shine.  
Because of your efforts  
And also of mine. ELP

## G R ounds For Scul P ture

I visited this phenomenal display of artwork in New Jersey with one of my daughters and her family. I found the sculptures to be fascinating but had not realized selected works were interpretations of paintings by Claude Monet and Renoir. Seward Johnson is the founder of this site.



East West Buddha – using ordinary objects, which in sunlight project to the surface below into the sitting Buddha.

When I go again, I will focus on the contrast of light and shadow and reread the section of *On Vanishing* as Lynn Casteel Harper explores the transformative nature of the sculptures depending on the time of day and the vantage points of the viewers.

# Se E ming To

Since we can never be absolutely certain about what a loved one is experiencing, as they advance in their cognitive decline, Harper suggests we use words like “It seems to me” when communicating our interpretation of events. I also like the caution “It appears to me,” which can be another choice of words to preface our remarks. Often, it appeared to me that Marsha was content and felt safe having me close by and I felt she trusted me to not leave her and that I would always look after her. Sometimes, she told me as much with her words and when words failed, she squeezed my hand in response to my squeezing her hand. She retained the same essence of identity as when I first met and fell in love with her. It seems to me that she knew changes were happening and she was not too sure what they meant.

**Thursday, August 17, 2023**

*“Thank you,” I heard you say  
Softly at the end of the day.  
Your face expressed such love  
I was touched like grace from above  
As your simple two-word expression  
Came out of the blue – my impression  
Of you changed – I don’t know how  
But I realized you have evolved now  
In a way that is more peaceful & serene  
As we live together in our daily routine.*

**01/08/24**

**M: Who are you? Why are you here?**

**E: I’m your best friend. I don’t want to be alone, so I am living here with you. Is that OK?**

**M: Yes, that’s OK. I don’t want to be alone either.**

**08/18/24**

**M: I like it when you’re here because when you’re here, everything’s going to be all right.**

**09/29/24**

**M: I’ve got everything I need because of you.**

**E: What a nice thing to say. Thank you!**

**05/22/24 (continued)**

**M: When will you be back?**

**E: I’m not going anywhere. I’m staying here with you.**

**M: (with tears in her eyes and a big hug) I’m glad you’re staying here.**

## Mis Recognition

I chuckled at the following account as I encounter a slightly different version when Marsha asks, “Why didn’t you tell me about my appointment with Dr. C \_\_\_\_\_?” or a similar future event.

*“One evening, as Sam helped his father get into bed, Mr. Kessler looked up and said in a kindly tone: ‘Who are you?’*

*Startled, Sam replied, ‘Your son.’*

*‘My son?’ Mr. Kessler said wonderingly. ‘How long have you been my son?’*

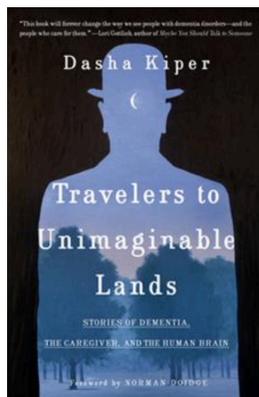
*‘Well, I guess sixty-two years now,’ Sam said, feeling both alarmed and amused.*

*Mr. Kessler’s eyes widened. ‘Sixty-two years you’ve been my son and only now you’re telling me?’*

*Sam laughed. ‘Well, sometimes it slips my mind.’*

*Seeing his son laugh caused Mr. Kessler to laugh as well.”*

(p. 17)



### Dasha Kiper *Travelers to Unimaginable Lands*