

## **Dementia Medical Poems**

*Poems (micro-stories) that may help you increase your comfort in talking about living in the dementia world, deepen your understanding of “psychiatric problems” and of moral injuries caused by our health care system, increase your compassion for individuals who have dementia and their family experiencing mental anguish (including yourself), and strengthen your own resilience*

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Acknowledgments: I am deeply grateful for the ever-present love of my wife and my son. I couldn't have experienced life's beauty or survived its horrors without their love, support, humor, and encouragement.

*Each of us literally chooses, by his way of attending to things, what sort of a universe he shall appear to himself to inhabit.*

- William James

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## What Is Dementia?

Dementia is a place  
where  
imagination trumps memory.  
Winds of grief  
and uncertainty  
are the only certainty.  
Chaos heads toward denouement  
rarely  
Understanding cause-and-effect  
an impossibility.  
Where “friends” quietly disappear  
and new friends quickly appear.  
Where the best teachers  
are lived experiences.  
A cold place  
warmed only by hugs.  
To survive,  
we must find meaning.  
To thrive,  
we must learn to create joy:  
Joy of dementia.



## **In Dementia World**

There are a lot of tears  
in dementia world,  
but they are always hidden.  
There are a lot of prayers  
in dementia world,  
all fervid, also hidden.  
Everyone thinks twice  
before risking fellowship  
with us who live  
in dementia world.  
Perhaps that is a good thing.  
They are sane,  
and God knows  
we need humor  
and beauty,  
not sanity  
in dementia world.



## Two Rules

Joyful conditions  
in living with dementia  
are never given.  
You will have to create them.  
Self-care, if properly directed,  
need not be divorced  
from wellness  
of the person who has dementia.  
In capable hands,  
two sides  
of the same coin.  
Two rules:  
Create your own weather.  
Self-care ought to be  
a communal asset.  
Always strive to follow  
these two rules  
if you wish  
to live well  
with dementia.





## **A Blessing for Caregivers**

May the love in your soul guide you.

May the courage within you overcome fears about caregiving.

May the heart within you conquer the pain involved in caregiving.

May you be given the best education and training, to overcome challenges in this journey.

May you have the commitment to care with compassion, to learn from failures, to be patient,

and be the best caregiver you can be.

May you have great respect for yourself.

May you show growing compassion and patience toward yourself as you come to realize how much

the well-being of (name of the person needing care) depends on you.

May you have the wisdom to hear

the unspoken gratitude (name of the person needing care) has for you.

And, above all, may you be given the wonderful gift of meeting the beauty that is within you.

May you be blessed, and may you find life enriched by your efforts of caregiving.

Adapted from John O'Donohue's poems

Caregivers are in reality care partners (receiving as much as giving)!

## **Dementia Joy**

Doc, living with dementia:  
what an incredible,  
life-affirming experience.  
Zooming with family regularly.  
Trying to achieve  
the impossible  
creatively.  
Helping each other survive  
through hard months  
of the pandemic  
barely.  
Now, enjoying,  
appreciating  
the joy of meeting physically  
hugging, kissing eagerly.  
Dementia has helped me see  
moral beauty,  
moral courage,  
and moral distress  
more clearly.  
Thank you  
for being there  
for me and my family.



Daughter of my patient who had advanced dementia and died peacefully at home after a fall, hip fracture, and hospice care. I explained the serious risks of hospitalization and surgery.

## Joy and Wonder

Dawn came.  
Snowing finally stopped.  
Sky turned blue.  
Air turned crystal clear.  
A gorgeous cold morning.  
Bitter cold,  
healing cold,  
cold that instantly stopped  
all pain.  
The mountains looked closer.  
Majestic,  
beautiful,  
every detail visible.  
Rocky outcrops,  
pine forests,  
tree lines,  
snow channels.  
Healing vision.  
Beauty that instantly stopped  
all pain  
and infused me  
with joy and wonder.



“Me” here is the wife of my patient who has advanced dementia and lives with him in beautiful Idaho mountains. She paints beautifully.

## **Dementia and Amazement**

My life, Doc,  
has become strange,  
a mosaic of fragments.  
Details and context fade  
or are recalled inaccurately,  
but feelings and experiences  
create a tapestry  
over time  
full of bad times  
but equally of good times.  
Dementia has made  
the remaining life  
a missed opportunity  
for many,  
but I have decided  
to start fresh  
and see every day  
as my first and last  
and be amazed  
at every step,  
every encounter,  
and take the sky  
into my arms.  
I plan to fly  
into the sunset  
with joy.



My patient's shift in attitude was inspired by Mary Oliver and Brother David Steindl Rast.

## Young-Onset Dementia Stress

Things keep breaking, Doc,  
again and again.

Everything seems broken.

Ground is always shifting.

Light is always flickering.

Dementia doesn't seem

to stop grinding

me down.

Problems won't cease

to be born,

and I am responsible

to fix them.

My grief rises.

My strength fades.

I cling to him

and he holds me.

The moment I cease

to cling to him

and he stops holding me,

my grief will engulf me

and my strength

will give out.



Wife (age 58) of my 62-year-old patient who has young-onset dementia.

## Fear of Dementia

I am not afraid,  
I tell myself.  
There is nothing  
to fear.  
I open the window,  
close my eyes,  
smell the fresh air,  
feel the soft evening breeze.  
I open my eyes,  
relax my mental concentration,  
and gaze at the stretched sky beyond  
and the solitary cloud,  
a beautiful white cloud,  
and decide to wait  
for the large bright moon  
that is eager to come out.  
The moon will give me,  
as it always has,  
pure solitude and tranquility.  
I release a deep breath  
and welcome  
this special momentary clarity.  
That there is nothing  
to fear.



My 80-year-old patient preparing for dementia assessment using mindfulness skills. He was relieved to find that he had mild cognitive impairment due to cerebrovascular disease and did not have dementia.

## **Fear of Alzheimer's**

I can't sleep, Doc.  
I am terrified.  
Fears clawing  
at my mind.  
Not even my tireless schedule  
gives any comfort.  
Ever since my mom's diagnosis,  
the Alzheimer's  
that has possessed,  
consumed, transformed her  
I dread  
will come for me.  
I can't seem to stop  
thinking my thoughts.  
I can't trust my mind.  
I have started relying  
on journals,  
which I keep  
with daily vigor.  
Help me, Doc.  
Please help me.



She is doing remarkably well after just 3 months of intensive mindfulness-based cognitive behavioral therapy.

## Not Alzheimer's

My patient gave  
a brave little nod.  
"You said the  
the test shows  
I don't have Alzheimer's."  
"That is so.  
Amyloid scan needs to be positive."  
No Alzheimer's did not mean  
no problems.  
She had vascular risk factors  
to worry about.  
But I saw no reason  
to frighten my patient  
with such information.  
My patient gave  
a cry of delight.  
"Thank you, thank you,"  
she said and left.  
It was a dreadful thing I did.  
Yet, it had to be done.  
Fear of Alzheimer's  
was paralyzing her.  
If there are gods,  
surely, they will forgive me.



My patient was a 30-year-old sweet and gentle person who had Down's syndrome.



## **Dementia Life**

Galloping paranoia  
Terrible tiredness

Reflection, contemplation  
Of the meaning of life  
Of nonsensical voyage

Praying for loneliness to end  
Reconnecting with solitude  
like an old friend

Gratitude for  
still being aware  
Drowning in a river of grief  
of losing  
my memory,  
my independence  
slowly  
but surely

Unpredictably attacked  
by anxiety storms  
of my future  
in nursing homes

Blown away by resilience  
of my brethren  
in early-stage support groups

Burning with rage  
at the callousness of leaders  
in rejecting all efforts  
to make communities  
truly dementia friendly

Meditating away this dementia life  
Jogging away from this dementia life



## Alzheimer's and Me

My life has been easy  
relatively, Doc.

Few privileges denied.

No stories

of resilience

of perseverance

of triumph of the will.

But

I am gregarious.

I can make friends easily.

I like me.

My wife likes me.

My friends like me.

Now, I worry

will Alzheimer's change me?

Will Alzheimer's change my personality?

Will I still be me?

Do tell me.

Please reassure me.



## Go Home or Die

“Doc, something is off.

He is irritable,

nervous,

sweating.”

I found him

woozy with narcotics

and panting

low, uncontrolled

staring rigidly ahead

eyes wide

and desperate,

drilling the darkness

outside.

“I want to go home

or die,”

he told me.

It explained everything:

the dread

the sense of doom.

He knew deep inside

that he was heading

toward a nursing home.

“Tell me about your home.”

He talked

and talked.

I listened

and listened.



He has been in the hospital for several days with advanced dementia. He has no family or friends, just one supportive neighbor. No nursing home or assisted living home will take him because he is “aggressive” and tries to leave. He is taking two antipsychotics and one antidepressant.

## Home Visit

“Doc, here’s your  
favorite tea and cookies.”  
“Homemade cookies  
to die for,”  
I replied.  
She smiled.  
“He is asleep.  
He is better.”  
“And you?”  
I asked.  
“Also better.”  
I raised my eyebrows.  
“Our daughter is coming to help.”

Her house was on a hill.  
I could see  
the panoramic vista beyond  
and the lush green golf course below,  
and in the other direction  
majestic mountains  
now snow-covered  
with the first snow  
of the season.

For the first time in months,  
we had a relaxed conversation.



“He” is my patient and has advanced dementia. “Better” = less agitated.  
She took my advice and reached out to their daughter for help.

## Long-Buried Sorrow

What is her yelling?  
A sign, a signal  
a symptom of moral anguish  
calling our souls  
to understand her plight.  
My patient had never learned  
to experience her feelings,  
as there was no one  
in her childhood or later  
who accepted her fully,  
who understood  
and supported her.  
And now, with advanced dementia,  
long-buried sorrow  
that could never be expressed  
is set free and  
only touch and soothing voice  
can do the miracle  
of bringing her some solace.  
No meds, please,  
No meds.



## Dementia Punches

Uppercuts

Hooks

Jabs

Roundhouses

Haymakers

And rabbit punches.

Dementia punches

keep coming, Doc.

They keep coming.

Bruised

Battered

Banged up

But I sweat no more, Doc.

I smile and wait

to be with my forever friends.

Sluicing rains

Whistling winds

Raw weather

Biting cold.

I spread my arms open

wide as my smile

as if to embrace them,

my forever friends.



My 76-year-old patient, a former NFL player who has mild dementia, trying to live on his own.

## Dementia Challenge

The diagnosis of dementia  
had stopped him in his tracks.  
The future looked cold,  
unpleasant,  
unwelcoming.  
No backtracking.  
Life pushes on  
relentlessly  
dead ahead  
inflexible.  
But one's perspective  
is flexible,  
he told himself.  
How to convert  
despair  
into hope?  
Even before that,  
how to stop  
being angry  
at life?  
It was a challenge.  
He liked a good challenge.



My patient is doing better, much better, with support from family, friends, our team chaplain, and mindfulness training.



## One Wish

“If you had one wish,  
what would it be?”  
My patient replied,  
“To feel happy.  
To skip away  
with a constant smile.  
To feel light on my feet.  
To feel full of energy.  
To turn face up  
breathe in the air,  
and feel  
that I am in an  
enchanted forest.  
Is that possible?”  
“Anything is possible,”  
I replied.  
“Not true.  
Not if you have dementia.  
No need to placate me.  
I am a big girl.”  
She smiled sadly.



## **This Is Love**

She had a sweet face,  
sharp eyes,  
thick auburn hair  
always out of place.  
She grinned  
at the sight of her pup.  
“The pup loves me  
even when no one else does,”  
she exclaimed.  
The pup nipped eagerly  
at her hand.  
She hugged her pup tight.  
The pup licked her ear  
and she giggled.  
“Best antidepressant, Doc.  
Thanks for recommending.”  
“You’re most welcome.  
I have never seen  
anything this effective.”  
“I have never seen  
such an adorable pup, Doc.  
This is Love.”



My patient named her pup “Love.” She had mild dementia with depression.

## **One Smile Is a Victory**

Weary of unanswered emails  
piling incessantly.  
Even more weary  
of the world  
that does nothing  
but rant.  
I replied to a few emails  
but soon realized  
that work was impossible.  
I reminded myself  
that in dementia world  
a smile from a patient  
is a victory.  
The world,  
with all its resources,  
will always fail  
to meet its responsibilities.  
But not everything  
was depressing.  
I had found my home  
in the dementia land.  
I had thrived spiritually  
despite or perhaps  
because of the pandemic stress.  
And my team had  
performed beautifully.



## Restraints

Another patient with advanced dementia  
in restraints:

Physical

Chemical

Again.

For trying to leave.

I still cannot believe  
that conditions so deplorable  
exist in our country's hospitals.

Perhaps I am naïve.

There is no humanity  
in our current system of care.

And no one cares.

No one is watching,

at least no one

with any real power.



## Thanks

My patient smiled,  
a smile that stopped me  
in my tracks.  
I found the smile  
unexpectedly pleasant,  
a vigor,  
a curious sweetness  
in it.  
There was also youth in it.  
A wild hope.  
Did all my patients with dementia  
have all this in them?  
Have I been blind  
for 23 years?  
I sat next to her,  
closed my eyes,  
and breathed quietly.  
I opened my eyes,  
turned toward her,  
and said, "Thanks."



23 years = my being a geriatric psychiatrist

## Homeless Dementia

It started raining at dusk,  
Steady, wetting rain,  
Very different from  
what my patient was used to  
living on the streets of Boise.  
He hunched in the jacket  
given by my nurse.  
Head down,  
walking away from the ED,  
trying to decide  
which shelter  
to shelter in.  
My nurse and I  
were terrified for his well-being.  
He had mild dementia,  
didn't want help,  
wanted pain meds  
for blisters on his foot.  
Our urgings  
had unsettled him.  
He was tired,  
demoralized,  
alone and wet.  
My nurse and I  
said to each other,  
"This is not right.  
This is not right,"  
as we helplessly  
watched him walk away.



ED = emergency department

## Despair

I stepped out of the hospital.  
I needed to walk.  
Began walking  
in no particular direction.  
God help me,  
I needed to walk.  
I watch the faces  
that pass me.  
Are they aware  
of the trauma  
my dementia patients  
experience in the hospitals?  
Do they care?  
When did they become  
so indifferent?  
I search in vain  
for answers.  
If our culture can treat  
people who have dementia  
with such disdain,  
it cannot be far  
from disaster.



## **An Angel**

The nurse aide  
washed the sweat  
from his face  
with a warm, damp cloth.  
Dressed him  
with deft, gentle hands.  
Wheeled him  
down to the dining hall.  
He was as light  
as a bundle of rags.  
The aide was determined  
to put some muscle on him.  
“Don’t you worry.  
I will make sure,”  
the aide assured  
his wife of 67 years.  
“Then, you both  
can plan your new adventure.”  
The wife smiled, turned to me,  
and said,  
“She is an angel.”



My patient (90 years old with advanced dementia, lost a lot of weight) and his wife loved traveling to remote places, their “adventures.”



## CPR and Dementia

She needed fresh air.  
CPR revived the patient's heart,  
but gave four rib fractures  
and a pneumothorax.  
The patient lived  
on life support  
long enough  
for her son to be with her,  
hold her hands,  
give her a last kiss.  
She walked down four flights  
to the street,  
stepped out  
into the cold evening air.  
Work hour traffic  
ground past her,  
slow and angry.  
Horns blared.  
Sirens barked.  
Fast pedestrians  
swerved by her.  
Somehow the frantic bustle  
settled her.



“She” is a physician assistant whom I supervise. An excellent, skilled PA. The patient was a 70-year-old mother who had advanced dementia. CPR is rarely successful in such situations. The short prolongation of her life was deeply meaningful to her son.

## Two Strangers

Two strangers  
in the land called dementia.  
I smiled. She smiled.  
I slowly moved  
my hand toward her shoulder.  
She slowly moved  
her hand around my waist,  
A beautiful side hug.  
While still hugging,  
I said things  
she didn't understand.  
She said things  
I didn't understand.  
We smiled. We talked.  
We went our separate ways.  
She forgot me.  
I did not forget her.  
She forgot my smile.  
I did not forget her smile.  
She forgot my hug.  
I vividly remember her hug  
and cherish this memory.



My patient has advanced dementia and significant fluent aphasia.

## Alzheimer's Disease

I had lost the thread  
of my thoughts.  
I was never one for  
solitary and gloomy reflections.  
I gathered up enough courage,  
slowed down my breathing,  
looked into her eyes,  
and said,  
“I have disheartening news  
to give you.  
Forgive me.  
You have Alzheimer's disease.”  
We were in the  
hospital chapel.  
Her favorite place,  
a place of great serenity  
and beauty.  
She closed her eyes  
and nodded.  
A trickle of tear  
sneaked out.  
She extended her hand.  
I held it in mine.  
I was glad we were in the chapel.



## Diagnosis of Dementia

My husband's doctor said  
he has dementia.  
I had trouble breathing.  
This cannot be happening.  
No, No, No,  
I told myself over and over  
as the world around me became blurred.  
I don't deserve this.  
He doesn't deserve this.  
We have been good people.  
We are not guilty.  
What do you think about  
when you suddenly realize  
that you have been banished  
from the "land of normal"  
and will never be allowed  
to go "home."  
The truth is  
that nothing will be clear,  
not for a long time.  
Too many raw emotions,  
random thoughts.  
Too much fear and anger  
to understand what is happening.  
All you will hear is  
No, No, No.



## Why Me?

Why did I  
have to get dementia?  
My chest felt tight.  
My mind went blank.  
It was hard to breathe.  
Then insight slowly dawned.  
I was trying  
logically to explain the illogical  
rationally to explain the irrational.  
Traipsing all over town  
desperately searching for some entity  
that would answer my question.  
I had to stop trying  
to unravel this knotty tangle.  
I had to stop measuring  
the distance that separated  
my heart from reality.  
I closed my eyes  
and took a deep breath.  
I was on the verge of tears,  
but I was able to  
hold it together.  
This is a good sign,  
I told myself.  
This insight.  
My tight face relaxed.



## Physician Cruelty

Her coldness toward her physician  
was not thawing one whit.  
I also felt outraged.  
He had said,  
“There is no cure.  
There is nothing we can do  
to slow it down.”  
“Words are wind.  
Just let them blow past you,”  
I beseeched her.  
“Some are cruel.”  
“Yes,” I agreed.  
Tension was rolling off her  
like steam from a fog machine.  
There was a tight little moment  
of the kind of silence  
that echoes round a room.  
Then she seemed  
to have disappeared  
in the quiet,  
the terrible darkness,  
the infinite cavern  
where one sits  
with the diagnosis.  
I sat with her  
trusting that sooner  
or later  
her resilience will awaken  
and we will return  
to the land of hope and action.



I was asked to give a second opinion for her diagnosis of Alzheimer’s disease.

## To Tell or Not to Tell

After the visit  
with his doctor,  
he headed straight  
to his favorite park.  
People coming,  
people going,  
people with dogs,  
people running,  
people at the hamburger stand.  
He sat on his favorite bench  
and stared ahead  
for a long time.  
Eventually, he decided  
to face the question:  
to tell or not to tell  
his family  
that he has Alzheimer's.  
To tell or not to tell.



He did tell. They are coping better than he feared. They are supporting him phenomenally. I was the doctor.

## No Driving

He climbed to the top  
and stood there  
for a long time  
until the sun vanished  
behind the saw-tooth mountains  
and darkness began to creep  
through the valley.  
Overhead  
the stars were coming out.  
He heard the great-tailed grackles  
before he saw them.  
They were not shy  
when it came to  
breaking the silence.  
The night was getting chilly.  
He traced his steps back,  
calmer and lighter  
than when  
he climbed to the top.



I had just recommended that my patient with dementia stop driving. Acceptance and being in nature had powerful healing effects for him.



## Dementia Rage

Rage has  
a stranglehold on me, Doc.  
Inside me,  
fear has manufactured  
a dark, desperate narrative  
where I am condemned  
to live  
within the limits  
of the present,  
a present that is  
soul crushing.  
The very notion of future  
fills me with anguish,  
for I am captive  
to Alzheimer's disease,  
confused by the complexity  
of modern living,  
estranged from the joy  
of independent living,  
aimless driving,  
effortlessly recalling  
happy moments  
with family and friends  
and just being.



## Dementia Caregiver

On the surface,  
peaceful mundane life.  
No rapids, no waterfalls.  
Quiet windless Wednesday.  
Mail carrier adeptly sorting mail.  
Ninety percent junk mail  
destined to be tossed away unopened.  
Inwardly, struggling to stay afloat  
Listening to Khalil Gibran's book  
*The Prophet*.  
The world suddenly  
comes to a halt.  
I couldn't move,  
My body numb.  
I was shaken  
to the core of my being.  
I had suddenly, somehow  
reached an understanding  
that emanates from  
the deepest, darkest recesses  
of one's being.  
No criticism,  
just understanding.  
Understanding that  
what I am experiencing  
is deep powerlessness,  
absolute impotence,  
formless, weightless impotence.  
Understanding that unless  
I accept this pain  
I will not experience warmth.



## Patience and FTD

My whole life  
felt encrypted.  
I was given  
the thumb drive  
that would decode,  
but no key.  
Life then had stuck me  
with a plan  
to find the key.  
But the plan was  
full of holes  
and more were appearing.  
I could sense  
the light of hope  
being shut off.  
I could feel the darkness.  
I could visualize  
a void around me.  
I started repeating,  
“Good things come  
to those who wait.”  
After the tenth time,  
I felt my body relax.  
My breathing became  
slower and deeper.



Teaching mindfulness to one of my patients (in her early forties) whose husband has autosomal-dominant young-onset Fronto-Temporal Dementia (and his two brothers also have it; the fourth brother doesn't have the gene). My patient is also worried about her three children getting FTD. I introduced my patient to the International NeuroPalliative Care Society.

## What Am I Going to Do?

“I am afraid  
I have bad news.  
Your husband has FTD,  
Fronto-Temporal Dementia.  
He is still unconscious.”  
“What am I going to do?  
We have four young kids.”  
“You are going to take  
one step at a time,  
one day at a time,  
one hour at a time,  
one minute at a time,  
one second at a time.”  
“OK.”  
“Starting now.”  
“OK.  
He was a good husband,  
a good father.”  
I nodded.  
“First thing,  
you need help.  
Who can I call for you?”  
“Jenny, my sister.  
Button 3 on my phone.”  
I dialed.



My patient is her husband, who was in a car crash, driving rashly due to FTD. FTD had changed his personality and made him mean, impulsive, and socially inappropriate. He was misdiagnosed as having Bipolar mania.

She is doing better with awesome support from sister, parents, spiritual community, dementia team, excellent disability insurance, and caregiver support groups.

## Sheer Terror

I was mumbling  
in indecipherable shrinkspeak  
as I tried to  
crawl out  
of a state of stunned disbelief.  
My thoughts  
a mush of rampant flashes.  
My inner debates  
raging over strategies  
that changed by the minute.  
Tears started to roll out.  
Tears not of sorrow  
but of sheer terror.  
My stomach flipped.  
I wanted to throw up.  
My body shook  
to my toes as  
my heart raced away.  
Where are you, Mom?  
Where have you  
wandered off to?



The plight of a psychiatrist caregiver whose mother (my patient) has dementia and had wandered away from home. After two longest hours of the daughter's sheer terror, my patient was found, safe and sound, several blocks away.

## Let the Tears Flow

I let the tears flow  
this time, without wiping them away.  
“No,” I thought.  
I’m not that lonely.  
I have my husband with me  
even though  
he can’t remember me,  
his wife of 44 years.  
I tell myself  
there are two of us  
looking up at the heavens,  
praying for joy to appear,  
reassuring myself,  
searching for joy,  
providing my husband with nourishment.  
Those are my duties now.  
This dementia has put  
shackles on my heart.  
Despair Anger Fear.  
I try to be hospitable.  
even to these visiting forces  
that constantly threaten  
to overwhelm me.  
Today  
I will let the tears flow  
without wiping them away.



Individual counseling is not the answer. Community, family and friends and pets always there in person to help the person with dementia and the care partner and to laugh together besides wiping the tears is the answer.

## Unthinkable Future

“Sorry. I am being rude  
Talking about you  
in front of you.”  
My patient who has dementia  
was pacing.  
She plunked herself  
into the chair  
and tucked her hair  
behind her ears.  
Her husband’s health was  
declining rapidly.  
He had no words.  
His soul felt too heavy.  
His wife in an ALF.  
That future was unthinkable  
at this moment  
and untenable  
when it arrived.  
His body revealed nothing  
of his psychic wounds,  
wounds that ran deep  
and felt permanent.  
“Ah, assisted living facility  
A place of boundless tranquility,”  
he quipped.  
“Humor is a good start,  
but we need more than a strong heart.  
No one can predict the future.  
Let’s live in the possibility  
that there is an alternate destiny.  
Let’s focus on getting you  
back to healthy.”



ALF = assisted living facility / community

## Anything but Dementia

Her clothes were brighter  
than a field of wildflowers  
with rich reds  
and sunny yellows.  
Countless shades of  
green and blue  
deep blacks  
and gray and purple.  
I had never seen  
such colorful elegance before.  
We sat on a bench outside,  
all bundled up.  
The air had begun to grow cold.  
She liked sitting here.  
The sun dipped below  
the tops of the trees.  
We watched a dragonfly  
move lazily among the reeds.  
“Why would they  
name it dragonfly?  
It looks nothing  
like a dragon.”  
We chatted about  
this and that.  
And more this  
and more that.  
Anything but  
her husband’s dementia,  
her struggles in keeping him home,  
his hallucinations,  
his anger,  
her guilt preventing her  
from asking her only son  
for help,  
her fears about the future,



and her grief.



## My World

I am a dementia caregiver.  
My world is desolate.  
Not a single living soul,  
not a bird,  
not a fly.  
Where waves roar  
for no one in particular.  
Where all events  
are beyond comprehension.  
Not a single logical thought,  
just reflections and reverie.  
Sinister at times  
and yet  
also filled with desire  
to look forever  
at the monotonous movements  
of the ocean waves.  
A prisoner  
of my own meditations,  
engulfed  
by an overwhelming sense of powerlessness,  
facing  
an inescapably bitter fate.



## Evening Loneliness

Evening came  
without you.  
It will leave  
without any of my pain.

Another evening  
no you.  
Evening will leave  
without taking my angst.

Evening came,  
so came tears.  
Evening will leave,  
but tears won't.

Someday  
evening will stop coming.  
Till then,  
I will keep hoping.

That one day, evening  
will bring you along  
and leave  
with my loneliness.



Loneliness experienced by many spouses of people who have dementia

## Moving in with Mom

My patient  
descended the hill quietly,  
the quiet broken  
only by a distant  
murmur of the river,  
the chirping of magpies,  
and the clacking  
of her sandals.  
A hawk was circling  
high above,  
dark against a blue sky,  
while below  
was her dog Brownie.  
A stone bounced  
down the slope  
disturbed by the  
passing paws.  
When she reached  
her car,  
she took a deep breath  
and called her brother.  
“I am moving in  
with Mom.”  
“Why? She will be fine.  
She will make it  
in that ALF we visited.”  
“I won’t be fine.  
I won’t make it.”



My patient’s mother (also my patient) has dementia and cannot stay alone safely. Her brother, she, and I talked about realities of living in an ALF in our Covid world.

## Your Mother Needs You More

My patient did not want to  
leave her father.  
“Your mother needs you more.  
Your dad is safe here,”  
I told her.  
What could she do  
but accede,  
praying that her father  
would live until  
she returns.  
Leave taking was hard.  
He did not even know  
her name when she came  
to say farewell.  
She kissed him  
on the brow  
and told him  
his little daughter was well.  
“I am terrified.  
I don’t want him  
to be alone  
when he passes away.”  
“He won’t be,”  
the nurse assured her.



My patient’s father died peacefully in the nursing home with the nurse by his side.  
His wife also had dementia and could not be left alone at home.

## Make Amends

Nothing is more vivid  
than the fact  
that you have no respect  
for yourself.

By being  
what you have become,  
by placing others  
always  
above yourself,  
you broke  
your own heart  
early  
and drove yourself  
away.

Time to make amends.

Today.

Now.

Make amends  
with yourself.

It is not too late.

Never too late  
to make amends.



My 66-year-old patient with childhood trauma from his father's abusive behaviors when drunk, now caring for him - father has advanced dementia.

With trauma-focused therapy and mindfulness, he has come a long way.

## The New 90

She was 90  
going on 60.  
Sharp as a tack.  
Slender, upright.  
Showed me pictures  
of her immaculate garden.  
Looked way younger  
than I was expecting,  
even after being warned  
by her daughter.  
“How’s my daughter doing, Doc?  
How bad is she?”  
“Your daughter  
is doing well,  
surprisingly well,  
although after meeting you  
I am not surprised.”  
She smiled.  
“So my son-in-law  
is not doing well.”  
I nodded.



My patient’s son-in-law has advanced dementia and was having severe hallucinations. The title of the poem indicates how many in their 80s and 90s are witnessing dementia in younger family members.

## God's Helper

"What is happening to me, Doc?

I have been shouting  
followed by a sudden flush  
of shame.

I am so tired.

My head hurts all the time."

"You have the flu  
and caregiver burnout."

"Any medicine?"

I again shook my head.

My 82-year-old patient  
had grown thin and frail  
but I could still feel  
the warmth of life  
through her skin  
as I held her hand.

Her voice was full of  
melancholy and despair.

"You will not die.

In fact, you will get better.

The worst is over,"

I said.

For the first time  
she smiled a little.

"You are too optimistic, Doc."

As I left her,

I wondered how in the world  
is she going to turn around.



My patient's husband has advanced dementia. She did turn around, thanks to our wonderful social worker, who did home visits and regularly took her outdoors to feed the squirrels. She felt she now had a purpose, as she was one of "God's helpers."



## You Are a Good Son

I hit the road  
headed east,  
no clear destination.  
Dawn happened  
an hour into my drive.  
The sky moved from dark  
to gray  
to purple  
to gorgeous orange.  
“Hello, sun.”  
Cruising at 80 miles an hour.  
Started music,  
Sheryl Crow music,  
“Everyday is a winding road.”  
My favorite way  
to settle myself.  
“You are a good son.  
Mom died peacefully.  
She is not suffering any more.  
You took good care of her.  
You are a good son.  
Feeling guilty is normal.  
There is always more  
one could have done.  
You are a good son,”  
I kept repeating.  
I kept repeating.



My patient’s son was truly a good son, and I told him so when I gave him the news. He took wonderful care of her for 6 years. She had advanced dementia.

## **Mom, Hang in There**

I perhaps gave him  
no real choice.  
Traffic was light,  
the journey long.  
The world outside  
dark quiet  
cold sleepy.  
His heart also quiet  
afraid, gloomy.  
He drove fast  
stopped for gas  
bought a stale sandwich  
that was made  
a year ago.  
Forced it down  
as he hustled  
to the hospital  
seven hours away.  
“Mom, hang in there.  
I am coming.  
Hang in there.”



I told my patient's son that his mother has advanced dementia, fell and fractured her wrist badly, has osteoporosis, and can't be discharged home. He came and took her home with home health. They both are doing okay now.

## Enter Slow Time

Stay home.  
Do nothing much.  
Just for a day.  
Yes, today.  
Cancel all appointments.  
Cancel all meetings.  
No TV watching.  
No news reading.  
No phone calling.  
No one is waiting for you.  
No one is getting worried.  
No one is getting mad.  
Walk your neighborhood slowly.  
Notice the smell.  
Notice the sounds.  
Notice your breathing.  
Slow it down.  
Enter slow time.  
Watch it pass by.  
Stay home.  
Do nothing.  
Just for a day.  
Yes, today.



My patient's daughter was burned out from caregiving responsibilities. She was fortunate to find a wonderful professional caregiver who was going to stay with her mother (my patient who has advanced dementia) for the whole day.

## Befriending Insomnia

The street was empty  
quiet  
no traffic  
no noise.  
The midnight air  
was cold,  
very cold  
below freezing cold  
way below freezing cold  
and strangely comforting,  
even beautiful.  
I have come  
to love it.  
“Insomnia is  
your new friend,”  
I told myself.  
“You would never have  
experienced a city  
in winter  
at midnight otherwise.”  
I reminded myself,  
“Be grateful.”



“I” is my patient’s daughter. My patient has moderate-stage dementia. Insomnia is one of the many gifts “living with dementia” has given my patient’s daughter. I am teaching her one of the five invitations by Frank Ostaseski – *Welcome everything, Push away nothing*. In this case, welcoming insomnia.

## Severe Attitude

He was dressed plainly  
Attitude severe  
Perspective unadorned  
Views out of date  
Emotional state gloomy.  
“That’s Dad.  
He doesn’t know  
how to help Mom,”  
his daughter said.  
I nodded.  
My heart went out  
for him.



My 80-year-old patient, his wife, has advanced dementia. His daughter is a total opposite of him, full of positive energy.

## Predawn Walk

It was cold,  
windy.  
The wind was bringing  
snow clouds.  
I could feel it.  
I could smell it.  
I turned up my collar,  
crossed my arms  
over my chest,  
trapped my hands  
under my biceps.  
I looked up:  
Full moon  
Perfect  
A new day  
Empty  
Unsullied.  
I began my brisk,  
superlong,  
dailyish  
predawn walk.  
My life-saving  
“medical” intervention.  
Life had become  
incredibly stressful  
since March 2020  
with no relief  
in sight.  
Maybe today  
will be  
a good day.



“I” is my advanced dementia patient’s son.

Maybe life will give him a break and relief will arrive in some form that he or I can't yet imagine.

## Sudden Dementia

“What should I do, Doc?”

“Take a walk

right now

alone

for as long

as you need.

Your sister can stay here.

Walking by yourself

will help.

Get some fresh mountain air.

See the trees.

See the sky.

Then come back.

We will chat.”

She nodded

and left

with tears

in her eyes.

She took two hours

to come back.



A massive stroke due to congenital vascular malformation leading to intracranial bleeding caused her husband to have severe aphasia and dementia. He is just 64. She is just 60. Two awesome kids. One awesome sister. She is slowly doing better.



## Lola

Lola is Ms. M's baby doll.

Lola is soft,

squishy,

the right size

to wipe away

Ms. M's tears.

Lola was initially

salmon-pink

with blue plastic eyes.

Now, a little grayish

and faded

with one ear stiff

from all the wiping

of tears.

Ms. M would wrap her

in her favorite

woolen scarf.

Ms. M would never

go to bed

without Lola.



Ms. M had severe dementia and lived in a memory care home. Doll “therapy” had brought her great joy. Ms. M has left us, and her daughter now cherishes Lola and the dried tears.

## What a Guy!

Hardscrabble childhood.  
No money, no frills.  
Dad working three jobs.  
Mom, the pillar  
of strength.  
Running water  
a luxury.  
Shoes rare.  
A square meal  
cause for celebration.  
Fast forward:  
college,  
doctorate,  
wife and kids,  
school superintendent,  
three books published.  
Wife has dementia.  
He wants to be  
a good caregiver.  
What a guy!



## Recipe for Success

“How do you do it?”

I asked her.

“Discipline, creativity,  
and machinelike consistency,”  
she answered .

Her success matched  
the roaring optimism  
of her personality.

I had never witnessed anything  
like this level of  
the caregiving success  
in a family  
living with dementia.

Her husband had  
advanced dementia

She was happy.

He was happy.

24 months in a row.

24 months since his diagnosis.

I was simply  
amazed and baffled.

Discipline, creativity,  
and machinelike consistency.

A recipe for success.



## Devoted Granddaughter

“I will move in  
and take care of her, Doc.  
Mom is overwhelmed  
and doesn’t have the patience.  
Grammy raised me  
with love and patience  
while my parents worked.  
Grammy is an artist, Doc.  
I don’t have those skills  
but I have her eye.  
My art collection  
is a testimony,  
you will see.  
But you will see  
a more literal resemblance.  
See this picture  
of Grammy  
when she was young?”  
“Looking at it is like –”  
“Looking in a mirror,”  
I finished her sentence.



My 82-year-old patient had advanced dementia.

## **Glorious Morning**

Christmas morning  
Just before dawn  
Bitter winds  
Fat lazy flakes  
An inch of snow  
on the ground  
Snowing got harder  
Air got colder  
Wind got wilder  
My kind of weather  
Glorious morning  
Not a soul out walking  
or driving  
Perfect  
Two inches of snow  
now on the ground  
Beautiful  
Merry Christmas  
I greeted myself  
Headed back home  
My lovely wife  
asleep still  
and hot chocolate  
waiting for me



My patient's husband loves his morning walks before his wife (who has advanced dementia) wakes up.

## Dementia and Suicide

“Why did he kill himself?  
Why, Doc? Why?”  
“He was a Marine.  
He had a code:  
unit, corps, God, country.  
Not being able  
to live independently  
was too much.  
He didn’t want  
to be a burden  
to his unit,  
his family,  
to you.  
He tried to,  
he really did.  
He pushed back suicide  
for days  
agonizing.  
He was just a person  
who couldn’t take any more,  
and in the end  
he did not betray  
what he believed in.”  
The daughter started crying.  
I said it again  
in different order  
with different emphases.  
It did not help.  
She kept crying.



Support from her family and friends and daughters of other veterans is helping.

## Tears Finally Came

Tears finally came, Doc.  
Tears finally came.  
A year has passed.  
I miss him.  
Miss his smile,  
Miss his hugs.  
He was a hugger, Doc,  
till the end.  
There is a gaping sinkhole  
in my heart.  
Everyone thinks  
I am doing well,  
and I am,  
but with a lot of effort  
and intentionality.  
We grounded each other,  
did everything together.  
Living with his dementia  
was stressful  
but meaningful.  
There was purpose  
and enough joy  
and laughter.  
I miss him.  
Enough about me.  
How are you doing, Doc?

