

FINDING THE SILVER LINING THROUGH CREATIVE EXPRESSION

Cynthia Knight Shares Her Story About Finding Her Voice and Paying It Forward

When Cynthia Knight's husband, Dean, was diagnosed with Lewy Body Dementia three years ago, their world changed overnight. Faced with overwhelming information and an uncertain future, Cynthia turned to poetry—an unexpected but powerful outlet. Drawing on materials from caregiver resources and her personal experience, she began crafting heartfelt poems during an adult education class.

What started as a personal coping strategy quickly grew into something more. Sharing her poetry in the UC San Diego Shiley-Marcos Alzheimer's Disease Research Center's Early Stage Support Group, Cynthia saw firsthand how her words resonated—sparking tears, laughter, and deep connection. Fellow caregivers began asking for copies, and she now shares her handmade booklets widely: with doctors, nurses, friends, the SMADRC E-newsletter, and support groups.

Cynthia's writing offers more than just comfort; it educates. With a background in education, she uses poetic forms like acrostics and Fibonacci sequences to express both her and Dean's perspectives. Through it all, poetry has helped her slow down, stay patient, and find meaning amid the challenges of caregiving.

Cynthia's journey is a reminder that even in the darkest times, creativity can be a light. Her work transforms hardship into healing—offering a true silver lining. The Shiley-Marcos ADRC monthly e-newsletter features one of Cynthia's poems each issue. Sign up to receive this digital publication in your inbox each month!



A new way to get along.
The tune has changed to our exchange,

We now dance to a different song.

We each now live in different realities,
Where simple chores seem massive.
You are scared it seems all of the time,

Shifting between hostile and passive.

As your memory loss cannot be controlled,
I require an abundance of endurance.
As you recede, I must proceed,

With patience and reassurance.

So during times when you're frustrated,
The times when you display fury,
I promise that I will comfort you,

So you don't have to worry.

There may be times of outbursts,
When a temper you might throw,
I will do my best to be forgiving,

My frustration I will try not to show.

Should your mind fail to remain on task,
And you continually forget a routine,
I will calmly repeat the instructions,

CAREGIVER TO LOVED ONE

by Cynthia Knight



I won't turn it into a scene.

Already there are times you struggle,
To find the right words to speak,
So we use our body language,

To relay the message you seek.

But if you should ever direct anger at me,
And try to push me away,
I will gently distract your attention,

For at your side I will always stay.

Eventually it may come to the point,
That it is I who you don't seem to know,
I won't take the matter personally,

I will be patient and go with the flow.

When chaos ensues and you get confused,
And you can't seem to understand,
I will look in your eyes and smile,

And I will gently hold your hand.

Going forward we have a new language,
A new way to get along.
The tune has changed to our exchange,
We now dance to a different song.

**Dealing
with
Dementia**

Poems
by
Cynthia Knight

INTRODUCTION

Dementia is a condition characterized by progressive, persistent, severe impairment of intellectual capacity, resulting from the loss of or damage to neurons in the brain. It is a condition that leads to death.

There are several different types of dementia. Each type presents a unique set of common symptoms.

- Alzheimer's:
 - memory loss.
- Lewy Body:
 - acting out dreams in sleep
 - seeing things that aren't there
 - problems with focus and attention
 - uncoordinated or slow movement, tremors, and stiffness
- Vascular:
 - trouble with problem solving
 - slowed thinking
 - loss of focus and organization
- Frontotemporal:
 - altered behavior, personality, thinking, judgment, language and movement.
- Traumatic Brain Injury
 - depression, explosiveness, memory loss
 - changes in speech.

My poems are meant to express emotions often experienced by people affected by dementia: specifically the **loved ones** who have dementia and the **caregivers** tasked with managing their care.

These poems are based on my personal experiences as a caregiver, and my interactions with other caregivers within various support groups,

CONTENTS

FACED WITH DEMENTIA	7
Diagnosis Dementia	8
Are You There?	9
Lewy's Infiltrating My Loved One's Brain	9
LBD is Killing Me!	10
We Don't Like Lewy	11
Storm Clouds	11
In the Eye of the Storm	12
"The Conversation"	12
Teeter Totter	13
Ticking Bomb	13
Overcrowded in ER	14
Dementia Does Not Define You	15
Blessings for a Loved One	15
CARING FOR DEMENTIA	17
A Change of Paradigm	18
Leaning upon Each Other	19
Caregiver to Loved One	19
Fear Not	20
Fading, Fading, Further Away from Me	21
Evolution of a Caregiver	22
A Caregiver Promise	22
Mourning You More Each Day	23
Caregivers' Burden	24
On This Long and Lonely Road	24
Caregivers' Support Group	25
Pity Party 9-1-1	27
Sending Out an S-O-S	28
Blessings for a Caregiver	29
Caregiver Self Care	29
Letting Go	30
Working Through Caregiver Grief	31
Caregiver Guilt	32
Facing Your Door	33
Bittersweet Farewell	33
There's Life After Dementia?	34

FACED WITH DEMENTIA

The symptoms of dementia often present gradually and might be dismissed as a normal part of aging, stress, or other ailments. Confronting your symptoms and limitations can be confusing and overwhelming. At some point, the symptoms become too difficult to excuse away and medical attention is sought. Tests are run, more doctor appointments are made and eventually a diagnosis is obtained.

The shock that you have dementia can cause a multitude of emotions: denial, fear, anger, anxiety, depression. . Grief sets in for the parts of you that are slowly dying. It can be difficult to acknowledge that you will gradually lose:

- your independence to drive,
- your ability to reason,
- your ability to learn new facts,
- your ability to communicate with the people you love,
- your memories,
- your dignity,
- your identity,
- and eventually your life.

Planning for the long term diminishes as you anticipate the future events that you will miss. You may feel frustration, humiliation and embarrassment as you relinquish control of your life to your caregivers.

DIAGNOSIS DEMENTIA*

I have dementia with Lewy bodies?
This can't be right, get another opinion (1);
I just conquered cancer, this just isn't fair! (2);
I often see people who aren't even there.

This can't be right, get another opinion.
Exercise, diet and crosswords may help?
I often see people who aren't even there;
My hands shake so much I can't use my phone.

Exercise, diet and crosswords may help! (3)
It's just no use, my symptoms get worse; (4)
My hands shake so much I can't use my phone;
Some days are clear, more often they're not.

It's just no use, my symptoms get worse;
I thrash in my sleep and I'm tired all day;
Some days are clear, more often they're not.
I'm forgetting my words; I'm becoming withdrawn.

I thrash in my sleep and I'm tired all day;
I'm struggling daily to complete simple tasks;
I'm forgetting my words; I'm becoming withdrawn;
This disease is relentless and there is no cure.

I'm struggling daily to complete simple tasks;
I just conquered cancer, this just isn't fair!
This disease is relentless and there is no cure.
I have dementia with Lewy bodies (5).

*and the five stages of grief

- (1) denial,
- (2) anger,
- (3) bargaining,
- (4) depression,
- (5) acceptance

o o o

ARE YOU THERE?

You are there, are you not?
Just around the corner, a bit out of reach,
A whisper, a side glance, a heartbeat away?

Are you real or an illusion?
You must understand the confusion;
I sense you, but see you not.

You seem to be watching my every move.
You know where I am at all times.
Your existence to others I cannot prove.

You taunt me from day to day.
Hiding each time I look your way.
I do not like this game you play.

What is it you want from me?
Is there something you want me to do?
You need to give me a better clue.

You think you scare me? Not a bit.
But you get on my nerves, I must admit.
I wish you would give up and SPLIT!

You're still there, are you not?
Just around the corner, a bit out of reach,
A whisper, a side glance, a heartbeat away?

o o o

LEWY'S INFILTRATING MY LOVED ONE'S BRAIN

Loved One's an oldie but he's a goody
Being bullied by one whose named Lewy.
As Lewy infiltrates my loved one's brain,
I'm relegated to observe in vain.

Lewy's a puppet who's pulling the strings,
Making my loved one do terrible things.
Unfortunately, much to my dismay,
Lewy grows stronger; he won't go away.

As Lewy's handhold on Loved One strengthens,
Loved One's grip on reality weakens.
Lewy plants suspicions and delusions,
Which leads Loved One to wrongful conclusions.

I can't fight Lewy, I must go along.
Armed with my knowledge, I must remain strong.
To provide my loved one stability,
I must maintain my own tranquility.

o o o

LBD IS KILLING ME!

I'm told I have LBD.
Why's this happening to me?
I ask how much time I've got.
Do they answer? They do not.

The symptoms, so I have read,
Will lead me to soil the bed.
The thought of this disgusts me.
I'm robbed of my dignity.

The time of day escapes me.
I'm not sure where I should be.
I can't join conversations,
Which weakens my relations.

I can't always find the word,
So my sentence becomes blurred.
My brain is slowly dying.
What sense is there in trying?

The guilt I feel is mounting.
Confusion is compounding.
I'm becoming less active.
My illness holds me captive.

LBD is killing me!
It's the reason I'm not free.
Not free to drive or travel.
A sentence with no gavel.

The world's closing in on me.
I can't fight or hide or flee.
I'm so disoriented,
The more I am demented.

o o o

WE DON'T LIKE LEWY

We don't like Lewy, do we?

He messes with your brain
He makes you feel insane
He trips you up so you will fall
He's really got some kind of gall

We don't like Lewy, do we?

He creeps into your life
He brings no good, just strife
He takes the very best of you
He knows there's nothing you can do

We don't like Lewy, do we?

o o o

STORM CLOUDS

As storm clouds descend upon you,
Darkness invades your soul.
Confusion and paranoia choke you like smog.

As storm clouds descend upon you,
Your sense of direction is lost in the fog.
A vortex of mistrust overwhelms your mind.

As storm clouds descend upon you.
Darkness invades your soul.

o o o

IN THE EYE OF THE STORM

We're in the eye of the nastiest storm.
Feeling off balance, unsafe and unsure.
It all began with the simplest of words,
"You have dementia and there is no cure."

We fought with fury against the high tides,
Seeing one doctor then seeing some more,
Reading some books and then trying some meds,
Tackling the symptoms became our new chore.

Now we just sit and we worry and wait,
Hoping for miracles, bracing for none,
Knowing just what will undoubtedly come.
Given the storm's not some thing we out run.

We know that when the storm finally ends,
There will be losses that many will mourn.
One of us certainly won't have survived.
One may be left truly battered and torn.

o o o

"THE CONVERSATION"

It's time for you to give up driving

There's nothing wrong with me

Your judgement is impaired by dementia

But I've never been in an accident

There's nothing wrong with me

Your car has suffered dents and dings

But I've never been in an accident

Everyone gets dents and dings

Your car has suffered dents and dings

If you injure someone you could be sued

Everyone gets dents and dings

I've been driving my whole adult life

If you injure someone you could be sued

Better to stop too soon than too late

I've been driving my whole adult life

You're taking away my dignity

Better to stop too soon than too late
Your judgement is impaired by dementia
You're taking away my dignity
It's time for you to give up driving

o o o

TEETER, TOTTER

Teeter totter, the scales have tipped.
Your once sharp mind has gradually slipped.
Lewy bodies have taken the reins,
Consuming regions of your brain.

Teeter totter, ebbs and flows.
Confusion comes, lucidity goes.
Lewy bodies have taken hold,
Stolen your youth and made you old.

Teeter totter, fragile gait.
You're slowing down as of late.
Dementia is a cruel disease.
It brings a person to their knees.

Teeter totter, highs and lows.
How much longer? Heaven knows.
But don't you worry, I'm by your side.
As you lose your way, I'll be your guide.

o o o

TICKING BOMB

Tick, tick, tick, tick.
A ticking bomb's inside your brain,
Destroying all that once was sane.

Quick, quick, quick quick.
Make the most of what you've got.
Don't dwell upon what you forgot.

Tick, tick, tick, tick.
Your time is coming to an end.
You've not got much more time to spend.

Quick, quick, quick quick.
Put your papers all in order.
Make the most of a recorder.

Sick, sick, sick, sick.
Your mind and body's failing fast.
The bomb within's about to blast.

Tick, tick, tick, tick.
A ticking bomb's inside your brain!
Once it explodes, there's no more pain.

o o o

OVERCROWDED IN ER

Rolling carts, bright lights, loud sounds
Ailing people all around
Doctors, nurses being paged
Patients screaming, in great pain

Hear them vomit, cough and moan
See them texting on their phone
Everyone's in a hurry
When's my turn, I do worry

Everywhere lights are blinking
I can't hear myself thinking
Stuck in the hall, all rooms full
My pain is high, my mind's dull

Doctors, nurses, labs techs, clerks
Testing meds to see what works
Monitors and needle sticks
Feeling dizzy, feeling sick

Nothing to drink or to eat
IV line's tangled in sheets
When I close my eyes to rest
I'm awakened for a test

My wife said she'd be right back
How long ago? I've lost track
Day? Night? There is no window
What's the Time? How would I know?

No call button for the nurse
I am feeling so much worse
Rolling carts, bright lights, loud sounds
Ailing people all around

o o o

DEMENTIA DOES NOT DEFINE YOU

Dementia does not define you.
Lewy bodies invade your brain.
You are brilliant and lovable, that's a fact.
Dementia does not define you.
Your heart and your soul remain intact.
You are precious and you are adored.
Dementia does not define you.
Lewy bodies invade your brain.

o o o

BLESSINGS FOR A LOVED ONE

May your symptoms be mild and manageable, and your good days outnumber your bad.

May your home be a peaceful and warm retreat, filled with soothing music and art.

May you have access to fresh air, gardens, and sunshine.

May you receive kindness and patience from those who care for you.

May you be comforted by loving family and friends.

May your resources stretch to meet your needs and comfort.

May you reflect on your life's accomplishments and say to yourself: "well done".

o o o

CARING FOR DEMENTIA

Taking on the role of primary caregiver for someone with dementia is usually done by the person most close to the one with the diagnosis. It is a position for which no one applies and which seldom comes with the benefit of education or training.

Caregiving is a complex role that evolves over time. It starts out with small chores to help the loved one and over time expands to include physical and emotional care. It comes with its own set of challenges, including:

- Increased household chores and responsibilities
- Adapting to a shift in the balance of power and duties.
- Developing new skills you didn't know you'd ever have to learn.
- Managing medical appointments, medications, and finances
- Dealing with symptoms and mood changes
- Managing one's own emotions while not showing frustrations in order to protect the loved one.
- Uncertainty about what promises to make.
- Dealing with family.
- Isolation.

A CHANGE OF PARADIGM

Where, dear, do we go from here?
I see you slipping away.
The changes may seem subtle,
But they worsen day to day.

We travelled far together,
Over many married years.
With your new diagnosis,
Our future is not so clear.

We weathered other hardships
Over finances and health.
Somehow we made it through them,
While building a modest wealth.

We're facing a new challenge,
That will put us to the test,
And strain our meager budget,
Which is bound to keep us stressed.

Our time may be soon over,
And I have a breaking heart.
Our vows were not forever,
Just until death do us part.

Dementia invades your brain,
And limits many a choice;
And I take on a new role,
As your memory and voice.

But this new path won't last long.
In this change of paradigm.
Where, dear, do we go from here?
We are running out of time.

o o o

LEANING UPON EACH OTHER

You can lean on me today
I'll lean on you tomorrow
Together we can make it
Through mounds of grief and sorrow

The kind of grief that we face
Is the kind that lasts for years
Without the help of others
One might drown in one's own tears

The tenderness you show me
When I'm feeling all rung out
Will be returned with comfort
When you're facing your self-doubt

o o o

CAREGIVER TO LOVED ONE

Going forward we have a new language,
A new way to get along.
The tune has changed to our exchange,
We now dance to a different song.

We each now live In different realities,
Where simple chores seem massive.
You are scared it seems all of the time,
Shifting between hostile and passive.

As your memory loss cannot be controlled,
I require an abundance of endurance.
As you recede, I must proceed,
With patience and reassurance.

So during times when you're frustrated,
The times when you display fury,
I promise that I will comfort you,
So you don't have to worry.

There may be times of outbursts,
When a temper you might throw,
I will do my best to be forgiving,
My frustration I will try not to show.

Should your mind fail to remain on task,
And you continually forget a routine,
I will calmly repeat the instructions,
I won't turn it into a scene.

Already there are times you struggle,
To find the right words to speak,
So we use our body language,
To relay the message you seek.

But if you should ever direct anger at me,
And try to push me away,
I will gently distract your attention,
For at your side I will always stay.

Eventually it may come to the point,
That it is I who you don't seem to know,
I won't take the matter personally,
I will be patient and go with the flow.

When chaos ensues and you get confused,
And you can't seem to understand,
I will look in your eyes and smile,
And I will gently hold your hand.

Going forward we have a new language,
A new way to get along.
The tune has changed to our exchange,
We now dance to a different song.

o o o

FEAR NOT

Fear
Not
I am
At your side
Here to take action
To protect and to comfort you
And to remind you how much you are loved and adored

o o o

FADING, FADING, FURTHER AWAY FROM ME

Delight my love, your life's been good.
You've lived your life the way you should.
But be aware it all will change.
Dementia soon will take the stage.
But before you part from sanity's sight,
Let's sing a song for love and life tonight.

Then here's to the loved one and here's to the hearts so true,
Who will think of you as the one we once knew.

Fading, fading further away from me.
Gradually losing your brilliance, voice and your memory.
Fading, fading further away from me.
Gradually losing your brilliance, voice and your memory.

Your life was once so bold and free,
But something's off, it's plain to see.
You hide it well from other's eyes,
So few can see through your disguise.
So you carry on like nothing is wrong.
Denial is now your favorite song.

Then here's to the loved one and here's to the hearts so true,
Who will think of you as the one we once knew.

Fading, fading further away from me.
Gradually losing your brilliance, voice and your memory.
Fading, fading further away from me.
Gradually losing your brilliance, voice and your memory.

On others now you must depend.
Your life will see an early end.
You struggle yet you fail to thrive.
You won't come out of this alive.
You are but a ghost of who you once were.
Your song's now a prayer you sing with a slur.

Then here's to the loved one and here's to the hearts so true,
Who will think of you as the one we once knew.

Fading, fading further away from me.
Gradually losing your brilliance, voice and your memory.
Fading, fading further away from me.
Gradually losing your brilliance, voice and your memory.

o o o

Evolution of a Caregiver

My nostrils start flaring
My eyes get to glaring
Whenever you act stubbornly
You bring out the beast that's in me

My blood gets to pumping
My feet start to thumping
When you don't do things that I say
Why must you provoke me this way?

I'm starting to just see
You don't mean to irk me
You're suffering from lots of pain
I know now that you're not to blame

I'm breathing real deep now
I'm getting good sleep now
I've donned a much thicker new skin
I've traded my growl for a grin

I've learned that with one touch
I can calm us so much
And we can be happy again
I'm feeling contentment within

My innermost beast's gone
I'm someone to count on
I promise my tantrums will cease
We can be together in peace

o o o

A CAREGIVER PROMISE

Truth requires reasoning, which you may be without **T**

Reality may be distorted and facts in disorder **R**

Understanding may not be possible for you **U**

Therefore, at times, I may resort to white lies **S**

However, I promise not to abuse your trust **T**

o o o

MOURNING YOU MORE EACH DAY

The person before me resembles you.
But the behavior I see suggests someone new.
You seem to be slipping away,
A little more from day to day.

You're words are few; your voice is weak.
You've not much to say when you finally speak.
You seem to be slipping away,
From week to week, from day to day.

You once appeared much happier.
But now you seem much snappier.
The you who was you is slipping away,
From hour to hour, from day to day.

You're not easy to keep amused.
You're more often than not confused.
The you I knew is slipping away,
From minute to minute, from day to day.

Your demeanor waxes and wanes.
There's less of the real you that remains.
The you I knew is slipping away,
From second to second, from day to day.

There's little of you within my reach.
Your armor's thick and hard to breach.
I mourn for the loss of who once was you,
And adjust to the someone before me who's new.

o o o

CAREGIVERS' BURDEN

Cook and clean, and advocate for loved one **S**.

Arrange appointments, medicines, and activi **T**ies.

Repeat and **B**e clear with instructions and di **R**ections.

Explain and el **U**cidate whenever confusion tak **E**s hold.

Gently di **R**ect loved ones through daily routine **S**.

Ignore ba **D** behaviors, insults, and ill temper **S**.

Voice conc **E**rns about symptoms and recent **F**alls.

Evaluate e **N**vironment for any risks that co **U**ld harm.

Respond with compassion and dignity at al **L** times.

Seldom getting adequate respite or sleep.

o o o

ON THIS LONG AND LONELY ROAD

For months and years I've missed him,
Even though he is right here,
A shell of who he once was,
Far away and yet so near.

As time rolls on without him,
On this long and lonely road,
My own needs take a back seat,
And I fear I might implode.

I worry about money,
And if I can make it last.
His needs are so expensive,
And our coffer's draining fast.

I worry about his health,
His weight and his appetite.
I worry about his moods,
And if they will cause a fight.

I worry I'm not enough,
That I don't have what it takes,
That I might fall apart soon,
That this burden's too much weight.

I worry that I'll get lost,
In the daily sweat and grind.
The person that I once was,
Has fallen ever behind.

It's true I miss him so much,
And the carefree days of old.
But it's me I miss the most,
If the truth is to be told.

o o o

CAREGIVERS' SUPPORT GROUP

We walk through the door with smiles on our faces.
We circle the room; take our usual places.
We turn off our phones and settle in our chairs.
We clip on name tags and pat down loose hairs.

"Who wants to go first?" makes us lower our heads.
Going first is something each of us dreads.
One caregiver bravely begins to speak,
Relieving the others for one more week.

One's loved one continues to roam in the night.
Trying to stop her, could lead to a fight.
One's loved one has trouble finding his words.
Another's one's speech is coming out slurred.

One caregiver spent yesterday crying,
Burdened with guilt, and tired of trying,
Trying to carry the workload alone,
Guilty her words employ too harsh a tone.

One misses passion they use to share.
Another, conversations that are no longer there.
One treasures moments of sweetness still left.
One feels her retirement's been subject to theft.

We hear about symptoms and ways for coping.
We learn about trials that get some of us hoping.
We've seen showtiming highs and sundowning lows
We learn when to use a Pinocchio nose (1).

"Anosognosia"(2) and "palliative"(3) are terms that we learn,
While listening closely and awaiting our turn.
Frustrations are stated and advice is shared.
Referrals are given for respite home care.

Though we each had our chance to contribute and vent,
We're reluctant to leave once our hour is spent.
The facilitator thanks us for our candor in sharing.
We should each take great pride in our efforts for caring.

- (1) **Pinocchio nose:** telling a harmless lie in order to gain cooperation from, or to sooth, a loved one who suffers from dementia.
- (2) **Anosognosia:** a neurological condition in which the patient is unaware of their neurological deficit or psychiatric condition. The difference between denial and anosognosia is that a person in denial rejects or avoids accepting reality because it's unpleasant or distressing. A person with anosognosia can't recognize the problem at all. Because they can't recognize they have a medical problem, people with this condition often don't see the need to care for that problem.
- (3) **Palliative:** a specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family. Palliative care provides comfort care with or without curative intent, as opposed to hospice care which provides comfort care without curative intent.

o o o

PITY PARTY 9-1-1

I used to hold a party
Every week, but not for fun.
It was a pity party
And was meant for only one.

For months I couldn't help it,
Down a spiral I would fall.
Alone I'd curse and I'd cry,
Clench my fist into a ball.

Doctors, friends and family
Didn't seem to understand.
They thought I had it covered.
They did not lend me a hand.

And then I heard a rumor.
There were people just like me.
People who were struggling.
So I had to go and see.

I went, I sat, I listened,
As they went around the room.
They listed out their problems,
Which resembled my own gloom.

But then there was a shifting.
Several people offered hope.
Their problems weren't much different.
They had learned just how to cope.

And when the meeting ended,
I had come to realize.
There were solutions for me,
If I'd open ears and eyes.

My pity parties ended.
I no longer moan and groan.
I go to weekly meetings.
I'm no longer all alone.

o o o

SENDING OUT AN S-O-S

Sending out an S-O-S
My sanity's in distress
Friends and family far and wide
I need you here, by my side

I need respite right away
I can't wait another day
The stress is too much to bare
I'm now in need of some care

Take some chores away from me
I need some time to be free
Let me get some long earned rest
I'm no longer at my best

Take our loved one for a walk
Take him twice around the block
Play him music, sing to him
Remind him of "way back when"

Stay with him a day or two
Look through pics of him and you
Let me have a good long break
Do it for our loved one's sake

I've been cranky I'll admit
Don't get me wrong, I won't quit
I've felt run down as of late
I need to rejuvenate

Answer now my S-O-S
Make my burden somewhat less
Rescue me with utmost speed
A good long break's all I need

o o o

BLESSINGS FOR A CAREGIVER

May you have the strength and patience of Job while managing your loved one's care.

May you have the humility to ask for help when your load becomes overwhelming.

May you be comforted by the support of loving family and friends.

May you find moments of peace and quiet in each and every day to allow your mind and body to rest.

May you get sufficient fresh air and exercise to maintain your own health and well being.

May you receive the respite you need at the times you need it most.

May you show yourself the same patience and kindness that you show your loved one.

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CAREGIVER SELF CARE

Credit yourself for your efforts.

Acknowledge your strengths.

R rejuvenate by stepping back.

Engage the help of others.

Get away to unwind.

Inhale deeply.

Voice your frustrations.

Enjoy the small successes.

Remember to love yourself.

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LETTING GO

I feel trapped, I feel cornered and my mind's over crowded.
I can barely see through a vision that's clouded.
I can no longer endure this status quo,
For the weight is quite crushing; it's hurting me so.

As my loved one grows weaker, I need to grow stronger.
I must come to terms: he's not himself any longer.
I need to let go of many a thing
That serve me no longer, yet to which I still cling:

wanting more, keeping score
expectations of what's fair
intimacy that's no longer there
feeling this burden is my only fate
misguided anger and misguided hate
holding my breath while waiting for death
fearing the end when I lose my best friend

By letting go of the tonnage to which I've held tight,
I banish the darkness and welcome the light.
I fill up the void that is left behind
With feelings of a more buoyant kind:

patience, acceptance
compassion, appreciation
understanding, rebranding
renewal, refuel

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WORKING THROUGH CAREGIVER GRIEF

DENIAL

When you hear the prognosis
You protest and reject it
So a second opinion
Will certainly correct it

ANGER

You are mad at your loved one
For a future that's scary
You are mad at the whole world
For it's not playing fairly

BARGAINING

If you put up a hard fight
You might beat this rotten deal
You'll try everything you can
Even beg, borrow or steal

DEPRESSION

Then your patience runs thin
And you spend your days crying
Not a thing that you do works
So what's the use of trying

ACCEPTANCE

You step aside and seek help
You find there's strength in numbers
You discover a respite
Can magically work wonders

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CAREGIVER GUILT

Carrying this guilt like a well-deserved prize,
Accused of betrayal, by the look in his eyes,
As I leave him behind and walk out the door,
Of the nursing home where he'll stay ever more.

For many years we have stood side by side,
He, my faithful husband, me, his loving bride.
I know he thinks now that I'm being unkind,
But I mustn't let him change my mind.

I can no longer keep him safe and protected,
While his brain becomes ever more infected.
This disease continues to multiply and spread.
It won't give up until it sees him dead.

Guilt is the price I will gladly pay,
For turning my back and walking away.
I know this decision's the best I could make,
So I'll keep a brave face for both of our sakes.

When I get home, I'll have a good cry,
And I won't stop 'til my tears run dry.
I'll ask myself questions and I'll second guess,
The decisions I made while under duress.

Why did I give up? Why did I concede?
Why didn't I do better? Why didn't I succeed?
Why did he get sick and leave me to cope?
Why did I give in and abandon all hope?

And then I will sleep, and dream of the day.
When insight and perspective will lead the way,
To abandoning the guilt that I've carried so long,
And crediting myself for being so strong.

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FACING YOUR DOOR

When I open the door to your room,
Will you be awake or asleep?
Will you be sick or full of gloom?
Will you be frightened? Will you whimper or weep?

When I open your door and ask how you've been,
Will you touch my face to see if I'm real?
Will you know who I am and welcome me in?
Will you agree to a shower or meal?

When I open your door and reach for your hand,
Will you be able to swallow your food?
Will you be able to rise and stand?
Will you be in an agreeable mood?

When facing your door, I'll always go in,
Regardless of what I might find,
Until that inevitable day comes when,
You leave me forever behind.

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BITTERSWEET FAREWELL

Toll the bell, fare thee well
From your life, from my sight, you depart
Even so, you remain, in my heart.

For so long, I was strong
At your side, day and night, taking care
Now I'm left, all alone; it's not fair

Life complete, bittersweet
Missing you, missing us, feeling blue
Without you, how will I, make it through

Loved one's passed, free at last
From disease, from all pain, from all fears,
Now's my time, to reflect, and shed tears

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THERE'S LIFE AFTER DEMENTIA?

"There's life after dementia,"
She says on each meeting day.
What does that mean to me now,
Since that day's so far away?

Dementia invades my home,
Every hour of every day.
Its permeating presence,
Tests my patience all the way.

I'm cooking, shopping, mending,
Cleaning house and paying bills,
And driving to appointments,
Keeping track of all the pills.

I can hardly catch my breath.
Most days I'm tired to the bone.
I would cry myself to sleep,
If I just had time alone.

Dementia's like a black hole,
Into which one disappears.
Losing track of who I am,
Is one of my many fears.

My family and close friends,
Try their best to lend a hand.
But they don't see what I see.
They can't fully understand.

So I keep seeking wisdom,
That support group offers me.
I hope I'll find my old self,
Once dementia sets me free.

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