

*Alzheimer's
Grief
Haiku*

Mary Todd

*A Haiku Blessing
for Mary's Journal*

May this be sacred.

May these writings be holy.

May you find healing.

*Blank journal and haiku blessing by Nancy
Niero 11/14/19*

gone but not yet gone
my heart aches beyond sadness
excruciating

Alzheimer's, you suck
"here" but not you any more
missing you so much

you in mem'ry care?
i don't think i can do that
i'll feel too guilty

eating lunch alone
no conversation partner
it's so quiet here

two-ten ... three thirty
four A M ... sleep evades
total exhaustion

sadness envelops
gather pink light in my heart
healing . . . breathe deeply

i hug you and i weep
it's so empty without you
i want the old Jim

for better, for worse
we had some fun times. We did.
this "worse" is the pits

you are so skinny
where's my mountain climbing man
I am missing you

slowing down is hard
they call it care-partner stress
burnout. where is peace?

sadness. emptiness
plumbing the depths of my life
sixty-two plus years

anoint me with oil
the void is deep, so deep
heal my broken heart

it is lonely here
don't worry 'bout tomorrow?
i want you with me

life is so different
there's a huge hole in my heart
looking for some sun

dementia's so hard
where is the you that is you
I need a warm hug

care-partnering's hard
you're in memory care . . . and
i'm still exhausted

unexpected tears
lump in my throat cuts off breath
i hate this disease!

this is what I want
to create moments of joy
for my beloved

I feel ill-equipped
that's not really true. I must
believe in myself

grief spills out of me
stored in my cells for so long
will it ever end

times of great sadness
you had the most caring heart
you touched peoples' lives

you were a pastor
and a DJ for church youth
your love . . . far reaching

hundreds of CDs
all jumbled together now
cannot enjoy them

you are down the hall
distance not measured by feet
cavernous absence

this slow withering
my grief is too much to bear
where is my center

intentional love
disease relentlessly pulls
I still love you so

as memories fade
love and loyalty abound
i'm still here for you

i light a candle
darkness overwhelms me
need to find some light

keeping love alive
even when the way is dark
help me find the ways

you have Alzheimer's
vascular dementia too
you can't understand

i get my hair cut
and I wonder how you are
thoughts are disjointed

reason doesn't work
but that's my natural go-to
what words can I use

life's so hard for you
I want to make it better
where do I begin

love is a feeling
but when that seems to be gone
love is an action

feeling untethered
shredding tapestry of life
ripping at my heart

soften my deep pain
deluge of ache and sorrow
in broken places

Jim, God is with us
this watching and waiting time
we are not alone

could I have this dance
anne murray's poignant lyrics
uncontrolled sobbing

picture's by the door
I kiss you each time I leave
keeps me connected

loving kindness now
in my listening and words
loving kindness now

you had a good day
Angelica includes you
you clean the white board

you have a good friend
you enjoy being with her
i'm glad you're happy

noise overwhelms you
you want to leave right away
it is just too much

Black Nativity
going out with family
I wish you could go

you call bingo games
Angelica calls cards first
you feel important

balloon volleyball
I love to see you happy
smile comes to my face

hospital ER
what? end of life decisions?
i am NOT ready

it's complete heart block
pacemaker's too invasive
what do i do now

i am doing fine
then why unexpected tears
who am i kidding

i want to scream
don't want anyone to know
keeping it inside

one day at a time
some of the days seem endless
they go on and on

help me, oh, help me
where do I turn for comfort
give me a cookie

you do love ice cream
it fixes most anything
thank goodness for that

friday the thirteenth
good grief! what will today be
same as other days

you keep losing weight
and I keep finding it. shit!
how does that happen

sometimes you try me
i know it's the disease ... but.
... be patient, Mary

shadows cover me
like a veil I can't see through
is there sun out there

feeling bottled up
tender words I want to say
get stuck in my throat

love has twists and turns
am i in or am i out
so fragile sometimes

shit. damn. fuck and hell
want to scream and yell and then
... i keep it inside

it just hurts sometimes
he doesn't know who I am
his mother? not sure

it's all right to cry
crying gets the sad out of me
I will feel better

(from "Free to Be You and Me)

by Carol Hall

driving on highway
tries to open car door
and scares me to death

phoenix in the fire
emerging that much stronger
re-born from the ash

another day dawns
don't want to get out of bed
let me sleep some more

it's dementia's fault
it's not really him talking
it's the disease

gas tank is empty
running myself in the ground
need to recharge me

listen to body
"if you don't, i'll shit on you!"
i didn't listen

the alzheimer's walk
pushing myself. don't feel good
shit myself. damn it

i'm gonna make it
keep plowing through these feelings
give myself 'nuf time

this is testing me
it's a challenge every day
but I can do it

is there a pathway
directions not very clear
need a GPS

accepting what is
is easier said than done
i don't like what is

no energy. pooped!
all i want to do is sleep
self care. NOW! do it

it's twelve degrees out
sit bundled on balcony
breathe and am grateful

remind me always
to find the holy in life
and to be thankful

i am numb. just numb
don't want to feel anything
not callous. just numb

you're leading the group
still a pastor in your heart
singing silent night

cried myself to sleep
tonight. uninvited tears
rest finally comes

classical music
soothes, nourishes dry places
my parched soul can drink

erases whiteboard
much like his mind, wiped clean
memory's not there

the sobbing tears kind
they're just under the surface
fall uninvited

blessed for brief moments
a spark of old self appears
he has happy times

grandfather chimes eight
we eat breakfast together
daily ritual

i must be patient
this is hard on you as well
hearts breaking inside

i will look forward
don't be overwhelmed by
grief and despair. move on

she just met Mr.
Rogers. it was Jim she met
he was just so kind

i can be a light
anoint my heart with blessings
heal myself ... others

images to keep
i hold your hand as we walk
to feel connection

i hardly know you
you're not a stranger and yet
am the stranger

disease rips off doors
i look inside and i stare
the room is empty

adapting to loss
necessary process
don't like it at all

life pushes and pulls
can't dance the same dance with you
you must lead this time

do the helpful thing
now different. difficult
landscape not the same

a spring in my step
today. Woah, that feels good
hey, 2020!

tender and hopeful
feeling like myself today
smile ... breathe ... enjoy

first intention of
the year. missed exercise class
i can do better

your feet are so dry

Julie makes you great food cream

you like the foot rub

i need some fresh air

howling january wind

invigorates me

“I feel awful. I

Can’t remember anything”

It doesn’t feel good

who is he really

this world of forgetfulness

how to know himself?

DEMENTIA TALKING

JIM'S WORDS

.....

see you tomorrow

“you are killing me, you know”

he wants me to stay

“Don’t bother to come

I didn’t mean that. Sorry”

It’s hard when I leave

can I give a kiss

“No. that’s just fake love.” parting

is real hard on you

“What did I do wrong

You want to get rid of me

I don’t understand.”

“we need to talk soon

about us. I feel like we

are falling apart”

this journey is hard

“are you seeing someone else?”

emotional toll

what is a good day?

when Jim doesn’t say to me

“I want out of here”

HOLIDAYS, BIRTHDAYS ... WINTER SOLSTICE ... NEW YEAR

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Thanksgiving is here  
what am I thankful for  
he is safe and well cared for

Grief on grief . . . birthdays,  
Christmas, anniversary  
Celebrating's tough

January three  
tied the knot in Kentucky  
till death do us part

nineteen fifty-eight  
water over and under . . .  
the dam didn't break

enjoy this day  
celebrate 62 years  
stay in the present

how can I make it?  
these Christmas celebrations  
sadness overwhelms

i just don't have it  
this decorating for Christmas  
maybe not this year

christmas is coming  
find new ways to celebrate?  
it's gonna be hard

uncontrolled sobbing  
decorations in a store  
honor my feelings

holiday grieving  
sharing joys together ... gone  
left with a dull ache

advent: wait and watch  
rejoice? i just don't feel it  
help my disbelief

what can I give Jim  
this season of gift-giving  
... the gift of presence

do not get depressed  
will this Christmas be your last  
stay in the present

breathe. breathe slow, deep breaths  
it's Christmas day; center self  
breathe in peace ... breathe out

create memories  
this Christmas season for our  
family feasting

can we think about  
just one memory to share  
from our childhood days

it's my birthday  
you have no idea. it's  
just another day

it's your birthday  
close your eyes and make a wish  
silence ... then. Amen!

jim, it's your birthday  
Emily brought you balloons  
to celebrate you

the winter solstice  
set intentions for the year  
need light for the way

on this darkest night  
light a candle in my heart  
to help find the way

walking in the dark  
promises that the path will  
lead, in time, to dawn

new year is waiting  
grief and happiness share space  
let me choose wisely

last month of the decade  
I couldn't have imagined  
the sadness to come

what's the big deal  
end of year . . . end of decade  
each day is new start

sanuary one  
Seek 20/20 vision  
for 2020

## **BREATHING SPACE**

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sitting at oceans edge
sunshine and lapping water
my soul is nourished

the four of us meet
we share our joys and sorrows
i am not alone

messiah concert
nourishing tender places
so good for my soul

mindfulness each day
language of recovery
i am so grateful

taking time for me
self-reiki at close of day
calming and peaceful

iphone camera
look for beautiful flowers
to capture beauty