

# **On the Path of the Perfecting Caregiver**

## **Multiple Perspectives From a Caregiver**

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**Affiliated with  
Communitas, Inc.**

**Included in this document are pages from a newsletter I developed in the early weeks of 2025. Communitas EST is distributed to a listserv of individuals who believe in and support the values of assisting individuals with disabilities to work, live and recreate in their local communities. The co-directors of this organization, Pat Beeman and George Ducharme have been friends for over 30 years and I asked them for space to record my reflections as a caregiver for my wife, Marsha, over the past three years as she lived life with dementia.**

# Communitas EST

Pat Beeman • George G. Ducharme: Co-Directors

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*"One candle in the  
midst of a circle  
represents the gift  
each one of us  
brings to others in a  
circle of support – a  
circle of friends"*

## Multiple Perspectives from a Caregiver

In this issue of Communitas EST, I will provide excerpts from my journal as the primary caregiver for my wife, Marsha, as she continues to live with a changing brain formally diagnosed as Alzheimer's. George and Pat have been mentors and friends to both Marsha and me over the past 30 + years. For two years I have used a weekly calendar type structure to record my thoughts, reflections and truths on this journey as well as tap into the wisdom of authors whose quotes resonate with me. I welcome this opportunity to share my work with each of you.

Ernest Pancsofar

page

- 2 Sample week's worth of journal items as I recorded them over the past two years.
- 3 Conversations between Marsha and Ernie
- 4 Poetic Expressions of my Journey with Marsha
- 5 Steps That Lead to my Basement on which I have posted 12 key words/phrases that influence my journey.
- 6 Sample Truths I Have Learned Along the Way from a Current List of 110
- 7 Reflections Using Meditation Card Prompts Provided to me by Pat Beeman
- 8 Lessons Learned as I Reflect on Strategies and Interactions I have had with Marsha
- 9 Acrostic Graphic Organizers: A Unique Way to Capture my thoughts in a more visual manner (3 pages)
- 12 Recommended Books that have influenced my points of view in the past two years.
- 13 Quotes by Ernie - - - Along the Way
- 14 Quotes of Note by Others
- 15 Second Sample week's worth of journal items
- 16 Final Thoughts

# A Week in Images and Quotes

October - 2024

## Conversations between Marsha and Ernie

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.

01/15/24

E: Some stores/places are closed and some are open today. Where would you like to go?  
M: Some place that's open.

04/25/24

E: It's a little cold to go outside in your nightgown.  
M: I could say a few things about you.

05/13/24

M: By the time we get there, we'll already be there!

05/22/24

E: Do you know when the best time of day is?  
M: No.  
E: Right now!

*I am amazed by how Marsha expressed herself throughout this past year. I chose these snippets to share with you, the reader.*

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.

06/17/24

M: You told me you'd come to bed now. (5:00 pm!)  
E: I'll be right in.  
After laying down for about 10 minutes.  
M: I'd like to get up now.  
E: OK.

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!

## Poetic Expressions of my Journey with Marsha

01/20/23

We may not see  
eye to eye  
and meet resistance;  
But we feel heart  
to heart at our very  
core essence.

02/25/23

Another week ends  
And each day tends  
To have unique ways  
To always amaze  
Me in what is true  
In all that we do.  
This Journey  
With Ernie  
Was not expected,  
Yet, I feel connected  
Strongly with you  
Through and through.

07/12/24

I am not a wealthy person  
But I certainly am a rich one.  
We are growing older together  
And when each day is done  
I am thankful for your presence  
You are the best person that I know  
And I continue to be surprised  
At just how much I grow.  
When I support and care for you,  
There's a richness in the air.  
Love surrounds and flows through us;  
We are a lovely pair.

*I enjoy expressing my thoughts and reflections in poems. Here is a sample of this outlet as I journey together with Marsha as her primary caregiver.*

05/21/24

Dishes and laundry are never quite done.  
Add cleaning and dusting to this ongoing fun.  
Reaching in the dryer I pull out some clothes,  
And think about where each of them goes.  
I wash dishes – just a few at a time  
Then read from a chapter of a book about crime.  
There is always something else that I could do,  
But right now I'm sitting on the deck with you.  
You center me in all ways that are good  
And if I look closely, I know that I could  
Figure out true meaning that's in my life  
Together as we live as husband and wife.

05/06/24

It's what it is;  
No more – no less.  
Life can be orderly.  
Life can be a mess.

But, there are lessons there  
Amid moments of the day  
Between the movements  
Of what we do and say.

The journey of two  
Includes me and you.  
The journey of Ernie  
Is mine alone to be.

Each incidence is not a coincidence.  
We can't predict the future  
But rest in the providence  
Of what will happen next  
To be taken in context.  
The love we share today  
As we each go on our way.

## Steps That Lead to Our Basement as Reminders of the Ingredients of My Caregiving Supports

*I wanted a visual reminder of key concepts/ways of being in my role as caregiver. I taped each word(s) on a different step going to our basement so that every time I went down or up these stairs, I would be reminded of the importance of each item in my day-to-day interactions with Marsha.*

**The journey** continues each and every day  
**Step-by-step** is the only way.

**Learning** is a process of making mistakes  
and after each one success often awaits

**Emergence** is the unfolding of our talents and gifts  
As the path ahead continually shifts.

**Uncertainty** is a truth that lingers near;  
It's a fact of life and not to fear.

**Togetherness** means more as we engage;  
And enjoy our lives at this elder stage.

**Mindfulness** is a way of life as we breathe and talk;  
And slow down the pace of the steps we walk.

**Small Steps** are necessary on the continual journey  
To bring peace and contentment to Marsha and Ernie.

**My Attitude** affects my moods from morning till night;  
Keeping it positive turns the darkness into light.

**Encouragement** is expressed in both words and silence.  
Keep things positive as I provide my assistance.

**Support** comes in many shapes and sizes,  
Depending on the exact challenge that arises.

**Acceptance** recognizes the limits of our abilities,  
But does not define the bounds of life's possibilities.

**Unconditional love** asks no questions and seeks no demands.  
Its message is felt when we hold each other's hands.



## Sample Truths I Have Learned Along the Way

*As I interacted with Marsha over the past four years, I wrote down ideas/suggestions that I would put under the broad category of “truths.” These truths work for me and may be worth exploring by readers who find themselves in a caregiving role. Here is a sample of the 110 truths . . . so far.*

**There is no “later” in your partner’s time! (3)**

**Avoid using the word “no” in conversations with your partner. (9)**

**All things are possible**

**Many things are probable**

**Some things are bound to happen**

**Nothing will change until I do! (10)**

**Be prepared to be interrupted. Put things down and go with the flow. Items on my to-do list can wait. (11)**

**There is no right versus wrong in our memories. Past events are only perceptions of what we believe to be true and are not worth arguing about. (12)**

**Take the responsibility to be wrong and mistaken following your partner’s comments about what has occurred in the past. (13)**

**When your loved one misplaces something of value, calmly react that something is missing and wonder where it may be. Place no blame. (14)**

**React to stories from the past, even though you have heard them many times, as if this is the first time. (17)**

**Next Thursday, Friday or Saturday may all mean the same. The only reality is right now! (26)**

**“I’m sorry.” is often the best response when being accused of an action from the past that you’re quite sure was not your doing. “I’ll remember not to do that in the future” is also not a bad response. (27)**

**When evaluating what course of action to take on any given day, think to yourself, “What would I say about this activity 10 years from now?” (28)**

**Sometimes outside supports cause greater stress than benefits. Your partner may not be ready for such supports . . . yet. (31)**

**A gentle approach to a perceived action is preferred over a verbal reprimand. (70)**

**We both have different memories of our past and we are both right to respect each other’s memories. (72)**

**Don’t argue facts.  
Look beyond the facts. (74)**

**Negative sounding feedback can be restated in more positive terms; i.e., instead of “Your shoes are on the wrong feet.” say, “This shoe would feel more comfortable on the other foot.” and instead of “You spilled some food on your gown.” say “Some food fell off your spoon.” (81)**

## Reflections Using Meditation Card Prompts

*Pat Beeman gave me a set of Meditation Cards with a word on each one to use as a point of focus for whatever we are going through at the time. My choice was to connect each word with my caregiving journey. Here is a sample of what I wrote for selected cards.*

### Clarity

#### *Meditation Card*

I remember when the first images were displayed from the Hubble telescope. There was a side-by-side comparison of a section of the universe before and after the use of the telescope. The clarity was amazing in the after photo. The entities were always there but it took a more powerful lens to bring clarity to what is. In a similar way we need a new lens with which to view individuals with Alzheimer's. The lens which we use brings clarity to who that person really is!

### Surrender

#### *Meditation Card*

*Instead of defining surrender as "giving up," I am using this term as "letting go."*  
*Let go of a need for predictable routines*  
*Embrace acts of improvisation*  
*Let go of a fear of the unknown for an unwanted disease*  
*Embrace the essence of Marsha's identity*  
*Let go of dreading making mistakes*  
*Embrace the journey of making new discoveries*  
*Let go of sadness*  
*Embrace memories that brought us to this current moment*  
*Let go of a need to be perfect*  
*Embrace the process of perfecting my supports*  
*Let go of self criticism*  
*Embrace reflection*  
*Let go of doing it alone*  
*Embrace sharing with a support group*

### Cleanse

#### *Meditation Card*

*I chose to review this key word as emotional cleansing and the following five statements surfaced:*

- 1. Accept current reality and support Marsha where she is at "right now."*
- 2. Maintain light classical music in background each day and "cleanse" my mind of local/national news – at least until 7:00 PM.*
- 3. Remember that all important activities will be completed, just not on an expected schedule.*
- 4. Avoid any negative feedback when Marsha experiences agitations and negative talk directed at me.*
- 5. Continue to share my thoughts and observations via my weekly journal.*

## Lessons Learned

*Often, at the end of the day, I would reflect on what I learned that day about providing better supports for Marsha. Below are three samples.*

**April 24, 2024**

Earlier this morning, Marsha refused to take her medicines. I waited about an hour and when she was looking out the window, I approached her again and offered her the medicines and she immediately brought them up and put them in her mouth. I'm not sure why she rejected them earlier, but I better understood the power of waiting and not trying to reason / explain the necessity of what she should be doing.

**July 20, 2024**

This learning occurs on my part if I am paying attention to events around me. I have noticed that Marsha appears to enjoy scraping her bowl to obtain the last bit of food. This occurred when she was eating her cereal for breakfast yesterday. A little while later I was having a very difficult time coaxing her to open her mouth for her morning medicines. Typically, if she does not take the medicines herself, I can put them in a small teaspoon of applesauce, and she'll accept them in her mouth --- but not today. She appeared quite confused no matter how I explained to her to open her mouth so I could give her the medicine. Solution: I put a small bowl of applesauce in front of her that included her medicines and told her this was the rest of her breakfast. Within just a few minutes she had scraped the bowl clean and taken her medicine.

**August 11, 2024**

Following our second trip in the car, Marsha told me she was not going in the house. I decided this was not an emergency and pulling her out of the car 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 until she decided to go in the house. After 5 minutes, I got out and invited her to join me in the house. Another 5 minutes elapsed, I poured a drink of juice and gave it to Marsha with the words, "Bring this glass back in the house when you are 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!

## Acrostic Visual Organizers

Shadow Side	In the Light
What Do You Need	D evelop Interdependence
A Lost Adventurer	E nrichment of "What Is"
Doom & Gloom	M eaningful Times Together
Dreadful Fatigue	E nduring Love & Connection
Sadness & Depression	N ew Sense of "Normal"
Dwell on What is Lost	T hankful for What Still Is
A Lost You and I	I welcome a "New Us"
Missing Parts of Me	A ccess to Marsha's "Essence"

<b>S</b> acred Space	
<b>U</b> nique Journeys	
<b>P</b> ersonal Stories	
<b>P</b> erspectives by Facilitator	
<b>C</b> Onnected	
<b>R</b> spectful Listening	
<b>T</b> ransitions	<i>My primary physician recommended that I join a caregiver support group. I searched for a group that contained many of my own values and found one at LiveWell in Southington, CT.</i>
<b>G</b> ratitude	
<b>R</b> outines Matter	<i>I captured my impressions of participating in this group with the SUPPORT GROUP acrostic summary.</i>
<b>N</b> O njudgemental	
<b>U</b> seful Information	
<b>P</b> ersonal Growth	

## Acrostic Visual Organizers (continued)

**I** nner Voice

*While sitting on our deck  
yesterday, I pondered on  
the elements of  
INTROSPECTION.*

*Give positive feedback  
And set the tone  
With affirming words  
In a negative-free zone.*

**N** etworking

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

*This Alzheimer condition  
Needs more exploration  
Just how do I fit in  
Amid this situation.*

**T** ender Moments

*Networking on-line  
With caregiving friends  
Provides me resources  
Some odds and ends.*

*My commitments  
To you made long ago  
I am here by your side  
Forever --- you know.*

**R** eframing

*Tender moments occur  
at unexpected times  
Be on the lookout  
Compose some rhymes*

*For no apparent reason  
Tension is in the air  
I go with the flow  
From here to there.*

**O** ngoing Experiences

*Reframing can put  
Events in a new light  
Turning a wrong  
Into a right.*

*Inspiration's knocking  
At my kitchen door.  
I welcome its presence  
I could use some more.*

**S** tress Reduction

*Our life consists of  
Ongoing Experiences  
Let's not get stuck  
Focusing on differences.*

*There are opportunities  
To figure out what to do  
I'll slow down and listen  
To feedback from you.*

**P** ositive Feedback

*Stress reduction breaths  
Relax my mind  
Calm my spirit  
From the daily grind.*

*Never Say Never!  
Be open to the call.  
There are no ANSWERS  
But options for us all!*

**E**xploration

**C** ommitments

**T** ension

**I**nspirations

**O**pportunities

**N** ever Say Never

Thank you for your presence  
I value your very essence  
As we enter our later years of life  
From a devoted husband to a beautiful wife.

Thank you for the warmth and care  
That I daily feel in the air  
When you're around I can plainly see  
Just how much you mean to me.

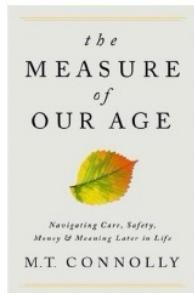
Thank you for our present and what will be;  
Our life is rich for both you and me.  
It's now a time for daily reflection  
To renew our love and daily affection. (ELP)

## Acrostic Visual Organizers (continued)

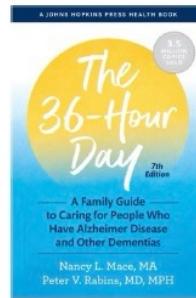
**We make gre *A* t company!**  
**We are here *F* or each other.**  
**Being mind *F*ul is necessary.**  
**It's a good *I* life my dear.**  
**Follow *R*outines daily.**  
**We are cal *M* and peaceful.**  
**We hold *h* *A* nds together.**  
**Quality *T*imes matter!**  
**I like grow *I* ng older with you.**  
**Let's do n *O* thing together!**  
**Nadya and *N* atyra are special daughters!**  
***S* low down!**



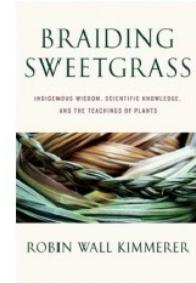
## Recommended Books



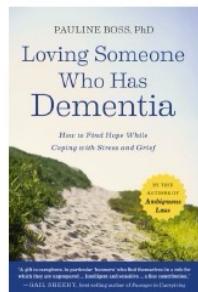
*“It was a perfectly good place and got the maximum number of stars. But none of those stars told you if you’d be treated like a human being or a chair.”*



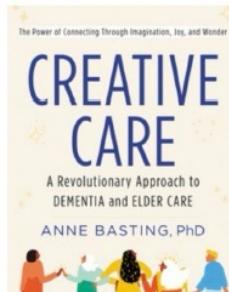
*The content affirms many of the approaches I believe to be beneficial for a loved one with a brain changing disease.*



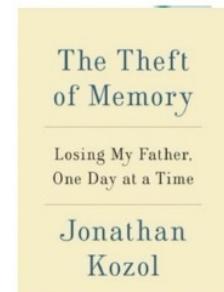
*“I like the ecological idea of aging as progressive enrichment, rather than progressive loss.”*



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



*“... 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.”*



*“My father’s life intensifies my feelings of respect for people who do not insist on too much certitude about the maps they’re using and do not insist on knowing in advance what destination they’ll arrive at in the ends of days.”*

## Quotes by Ernie --- Along the Way

October 3, 2024

*Today is Thursday:  
a PERFECTING day - a  
day to practice again!  
There will never be a  
perfect day, but there  
will always be a  
PERFECTING day!*

October 21, 2024

*WHAT will be will be.  
HOW will I look within to  
see ...  
WHY these events are  
happening to me  
WHERE our paths both  
lead to eternity?  
WHAT will Marsha teach  
me today?  
HOW will I show my love  
in what I say?  
WHY are these events  
happening in this way?  
WHERE is the path to  
being?*

April 7, 2024

*Several months ago, I  
decided not to oppose  
Marsha on purchases in the  
grocery store. If I could not  
redirect her choices, we  
bought what she selected  
often to go uneaten at  
home. To offset this waste, I  
now make a monthly  
donation to the Covenant  
Food Kitchen. I'm not  
necessarily recommending  
this approach, but it works  
for me.*

October 15, 2024

*Marsha was accepted  
into Hospice (Comfort  
Care) today and more  
supports and services  
will be coming her way.*

November 2, 2024

*What can I learn from  
my interactions with  
Marsha today?*

*How is what I am doing  
today an improvement  
on what I was doing  
yesterday?*

*What am I discovering  
when I sit in silence and  
just breathe?*

*What contributions can I  
make to other  
caregivers when I  
describe my journey  
among the entries of  
this journaling?*

April 24, 2024

*After an hour-long drive in  
the car Marsha turned to  
me prior to exiting the car  
and said, "I want to ask you  
something. Do you ever  
have times when you know  
something is not right, but  
you just keep on going?"*

June 4, 2024

*As your brain changes, I am changing too.  
As we age together, I pledge my love to you.  
My life is different than what I had expected  
Much richer and meaningful as we are connected  
To the beauty life has to offer each and every day  
As we live together in a mutually contented way.*

September 1, 2024

*It's like Groundhog Day,  
the movie. Every day  
similar events unfold but I  
have a new opportunity to  
respond differently based  
on my cumulative  
experiences with each  
preceding "same" day.  
Each day can be better  
than the one before . . . if I  
find respectful and  
dignified ways to support  
Marsha.*

July 16, 2024

*Respond to hurtful  
words ... with peace  
Respond to anger ...  
with love  
Respond to confusion ...  
with understanding  
Respond to agitation ...  
with peace.  
Respond to frustration  
... with love  
Respond to clutter with  
understanding  
As Nick Lowe aptly  
wrote (What's So Funny  
'bout) Peace, Love and  
Understanding.*

## Quotes of Note by Others

March 3, 2024

*Everybody is wondering what and where  
They all came from.  
Everybody is worrying about where they're going to go  
When the whole thing's done.  
But no one knows for certain and so it's all the same to me.  
I think I'll just let the mystery be.*

*Iris DeMent*

January 14, 2024

*When we honestly ask  
ourselves which  
person in our lives  
means the most to us,  
we often find that it is  
those who, instead of  
giving advice,  
solutions, or cures,  
have chosen rather to  
share our pain and  
touch our wounds  
with a warm and  
tender hand.*

*Henri Nouwen*

April 7, 2024

*The memory of the  
heart was far  
stronger than  
whatever was kept  
in the mind.*

*Louise Penny,  
Kingdom of the  
Blind, p. 3*

March 1, 2024

*"What day is it?" asked  
Pooh.  
"It's today," squeaked  
Piglet.  
"My favorite day," said  
Pooh.*

*A. A. Milne*

April 1, 2024

*The events in our  
lives happen in a  
sequence in time,  
but in their  
significance to  
ourselves they find  
their own order, . . .  
the continuous  
thread of revelation.*

*Eudora Welty*

November 10, 2024

*We have never arrived.  
We are in a constant  
state of becoming.*

*Bob Dylan*

March 16, 2024

*We must let go of the  
life we have planned,  
so as to accept the one  
that is waiting for us.*

*Joseph Campbell*

December 7, 2024

*I wish to say what I  
think and feel today,  
with the proviso that  
tomorrow perhaps I  
shall contradict it all.*

*Ralph Waldo Emerson*

December 8, 2024

*A lot of my loved one's  
15 years with  
dementia were very  
positive for me, and  
my presence seemed  
always to be a positive  
thing for him. I miss  
him very much in both  
of his modes, pre and  
post. There was much  
good in both.*

*Carol Connolly*

May 26, 2024

*Just watch this  
moment, without  
trying to change it at  
all. What is  
happening? What do  
you feel? What do you  
see? What do you  
hear?*

*Jon Kabat-Zinn*

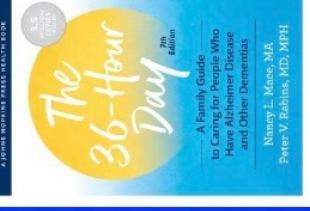
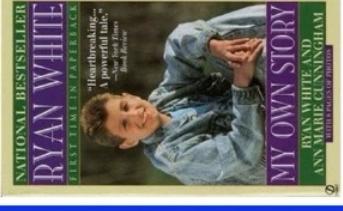
April 2, 2024

*Forever is composed of  
nows.*

*Emily Dickinson*

## A Week in Images and Quotes

December - 2024

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
01	02	03	04	05	06	07
<b>Old is that age we are not yet.</b> M.T. Connolly, <i>The Measure of our Age</i> p. 286	<b>... I read books I haven't read for decades and they seem very different now than how I remember them. The books haven't changed, but I have.</b> M.T. Connolly, p. 294	<b>Know that you are the perfect age.</b> Each year is special and precious, for you shall only live it once. Be comfortable with growing older. Louise Hay	<b>No straight lines make up my life; And all my roads Have bends;</b> There's no clear-cut beginnings; And so far no dead-ends. Joan Didion	<b>For there is no friend like a sister in calm or stormy weather;</b> To cheer one on the tedious way, to fetch one if one goes astray, To lift one if one totters down, to strengthen whilst one stands. Harry Chapin	<b>Ryan White would have been 54 on this date. He would be on my short list of who a "hero" is.</b> 	<b>I wish to say what I think and feel today, with the proviso that tomorrow perhaps I shall contradict it all.</b> Ralph Waldo Emerson
<b>Life is about shifting the balance in favor of change and try as we might to hold on forever to the best of moments, it's simply impossible.</b> Susan Krauss Whitbourne	<b>I write entirely to find out what I'm thinking, what I'm looking at, what I see and what it means. What I want and what I fear.</b> John: You had the occasion to see this excellent musician and, if I recall correctly, you were quite impressed. Louise Hay	<b>I'm beginning to understand myself. But it would have been great to be able to understand myself when I was 20 rather than when I was 82.</b> Dave Brubeck	<b>Let us not look back in anger, nor forward in fear, but around in awareness.</b> James Thurber	<b>There is no recipe to be a great teacher, that's what is unique about them.</b> Robert Sternberg	<b>I do find that there's a fine balance between preparation and seeing what happens naturally.</b> Timothée Chalamet	<b>You must distinguish between what is urgent and what is important. You could accomplish all of the urgent things that you desire without accomplishing anything that is important.</b> Gary Zukav
<b>But he that dares not grasp the thorn should never crave the rose.</b> Anne Brontë	<b>I'm a background person.</b> J. J. Cale	<b>I feel quite comfortable being a "background person."</b> You must distinguish between what is urgent and what is important. You could accomplish all of the urgent things that you desire without accomplishing anything that is important.	<b>Life's challenges are not supposed to paralyze you, they're supposed to help you discover who you are.</b> Bernice Johnson Reagan	<b>I have often thought that some of our potentially great teachers would also have been potentially great teachers elsewhere. They just chose to come to CCSU on their path to become a great teacher. (ELP)</b> The ongoing discovery of who I am is enhanced as I experience my role as caregiver for Marsha. This is a gift and one I value immensely. (ELP)	<b>Problems arise in that one has to find a balance between what people need from you and what you need for yourself.</b> Jessye Norman	<b>I may have referenced this book in a prior posting. The content affirms many of the approaches I believe to be beneficial for a loved one with a brain changing disease. (ELP)</b> 



***A Circle of Support surrounds you  
Whether you are aware of who they are:  
People who are in your life  
Who love you both near and far.***

***They have a commitment and purpose  
To provide more choices for you  
To lead a life of dignity  
And to be content in all you do.***

***The challenges will be many  
In the weeks and months ahead.  
But, we are here to guide you  
And be your golden thread.***

**My sincere thanks and appreciation to George and Pat for allowing me space to share my journey with Marsha as her primary caregiver. My life is enriched and blessed by this “unexpected” role. If you would like to receive copies of my weekly entries beginning now – please let George and Pat know.**



**I am thankful for all the events from my past;  
I am aware of the events of today;  
I anticipate the events of the future with cautious optimism. (ELP)**

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