Communitas EST

Pat Beeman • George G. Ducharme: Co-Directors

VOLUME 17, No. 1 – Spring, 2025

"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

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TJLESDAY TUESDAY TUESDAY Mart I keep being reminded of is how everyone who is alive how point is all how everyone who is alive how a solution and abilities. Hen Kivnick as Hen Kivnick as duoted by Anne Basting in Creative Care, p. 193 Marsha was accepted into Hospice (Comfort Care) today and more supports and services will be coming her way. Life is all memory, except for the one present moment that goes by you so quickly you hardly catch it going. Tennessee Williams Unless they've had some experience with it, the hospice is still a mystery to most popple. Because hospice deals with death, people tend not to talk about it. Art Buchwald	
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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 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-byside 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:

- Accept current reality and support Marsha where she is at "right now."
- 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.
- Continue to share my thoughts and observations via my weekly journal.

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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

July 20, 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.

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



- **S** acred Space
- U nique Journeys
- ersonal Stories
- erspectives by Facilitator Ρ
- CO nnected
 - **R** spectful Listening
 - ransitions

G ratitude

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

- **R** outines Matter
- N O njudgemental
 - U seful Information
 - ersonal Growth

Southington, CT. I captured my impressions of participating in this group with the SUPPORT GROUP acrostic summary.

Acrostic Visual Organizers (continued)

- nner Voice
- N etworking
- T ender Moments
- **R** eframing
- O ngoing Experiences
- **S** tress Reduction
- **P** ositive Feedback
- **E** xploration
- **C** ommitments
- ension
- nspirations
- **O** pportunities
- N ever Say Never

- While sitting on our deck yesterday, I pondered on the elements of INTROSPECTION.
- My inner voice speaks No one hears but me. Wisdom and guidance Are offered for free.
- Networking on-line With caregiving friends Provides me resources Some odds and ends.
- Tender moments occur at unexpected times Be on the lookout Compose some rhymes
- Reframing can put Events in a new light Turning a wrong Into a right.
- Our life consists of Ongoing Experiences Let's not get stuck Focusing on differences.
- Stress reduction breaths Relax my mind Calm my spirit From the daily grind.

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

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

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

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

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

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

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

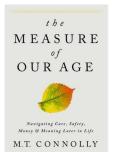
Thank you for your presence I value your very essence As we enter our later years of life From a devoted husband to a beautiful wife.

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.

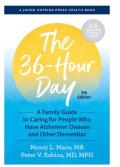
Thank you for our present and what will be; Our life is rich for both you and me. It's now a time for daily reflection To renew our love and daily affection. (ELP) **Acrostic Visual Organizers (continued)**

We make gre A t company! We are here F or each other. Being mind F ul is necessary. It's a good I ife 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!



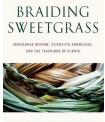


"It was a perfectly good place and got the maximum number of stars. But none of those stars told you if you'd be treated like a human being or a chair."



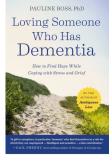
Recommended Books

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

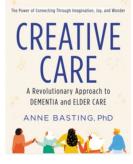


ROBIN WALL KIMMERER

"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." The Theft of Memory

Losing My Father. One Day at a Time

Jonathan Kozol

"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 vesterday?

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.

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*

December 8, 2024

Iris DeMent

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

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

A Week in Images and Quotes December - 2024	SATURDAY OT OT OT OT Nikih to say what I think and feel today, with the proviso that tomorrow perhaps I shall contradict it all. Ralph Waldo Emerson I shall contradict it all. Ralph Waldo Emerson Nou don't get to choose how you're going to live. Now. Joan Baez Joan Baez I do find that there's a fine balance between preparation and seeing what happens naturally. Timothée Chalamet Problems arise in that one has to find a balance between what people need from you and what you need for yourself. Jessye Norman
	FRIDAY 0 0 0 0 0 0 0 0 0 0 0 0 0
	THURSDAT FRIDAT 05 06 05 06 06 06 07 06 08 06 09 06 010 06
	VEDNESDAY OL OL No straight lines make up my life; And all my roads have bends; There's no clear-cut beginnings; And so far no dead- ends. Harry Chapin Harry Chapin Let us not look back in anger, nor forward in fear, but around in awareness. James Thurber Life's challenges are no supposed to paralyze you, they're supposed to help you discover who you are. Bernice Johnson Reagon The ongoing discovery of who I am is enhanced as caregiver for Marsha. This is a gift and one I value immensely. (ELP)
	TUESDAY O O 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. Joan Didion Joan Didion Joan Didion I'm beginning to understand myself. But it would have been great to be able to understand myself. But it would have been great to be able to understand myself. But it would have been great to be able to understand myself. But it would have been great to recipe to be a great teacher, that's what is unique about that some of our potentially great teachers would also have been potentially great teachers ocome to CCSU on their path to become
	NONDAY NONDAY Proven't read for thaven't read for thaven't read for thaven't read for thaven't read for thave and they seem very different now than how I remember them. The books haven't thanged, but I have. M.T. Connolly, p. 294 John: You had the occasion to see this excellent musician and, if I recall correctly, you were quite impressed. I'm a background person. J. J. Cale I'm a background person. J. J. Cale I'm a background person. J. J. Cale I'm a background person. Secondisish person. Marken what is urgent and what is important. You could accomplish petween what is important. You could accomplish petwor. Sary Zukav Gary Zukav
	SUNDAY SUNDAY Old is that age we are not yet. M.T. Connolly, The measure of our Age p. 286 p. 286 p. 286 p. 286 p. 286 Measure of our Age p. 286 p. 286 p. 286 Low that you are the perfect age. Each year is special and precious, for you shall only live it older. Louise Hay Life is about shifting the balance in favor older. 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. Susan Krauss Whitbourne But he that dares not grasp the thorn should never crave the rose.

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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.

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.



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)

Direct all inquiries regarding the content of this edition of Communitas EST to

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