

On the Path of a Perfecting Care Partner

Perceptions Along the Way

Version 2

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It was, and still is, an

Marsh **A**

****D**ementia**

Li **Ved Experience**

Be G **Entle**

Be Ki **Nd**

Be Considera **Te**

The Lang **Uage We Use**

Lessons Lea **Rned**

What's N **Ext?**

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Story 1: Getting Out of the Car

We arrive back home and I said to Marsha, “OK let’s go inside.”

She didn’t make any move to get out of the car.

I paused and wondered what to say next.

Be Gentle / Be Kind / Be Considerate

I said, “It looks like you’re not ready to go inside yet, I’ll wait out here with you for awhile.”

After about five minutes, I said, “I’m going inside now. Please come in when you’re ready.”

I left and went inside.

Another five minutes went by and Marsha did not get out of the car.

As I prepared a drink, I got an idea. I poured a second drink for Marsha and took it outside and said. “I thought you might like a drink of lemonade. Bring the glass in the house when you’re through.”

About three minutes later, as I looked outside the living room window, I saw Marsha drink her lemonade, open the door and bring the glass inside.

What would I have done if this response had not worked?

I don’t know!

I Was Gentle / I Was Kind / I Was Considerate

Story 2: There is a Man Staring at Me Through the Window

One night Marsha announced to me that a man (our next-door neighbor) was staring in at her through our bedroom window.

I paused and wondered what to say next.

I went to the window and could have said, “There’s no one out there. It’s just your imagination.”

That response would not have been

Gentle / Kind / Considerate

Instead I said, “He’s gone. We must have scared him away. I don’t think he’ll be back.”

I continued: “I will order some thicker curtains that are called “black out” curtains and no one will be able to look in at you through those curtains.”

Marsha settled back and said, “OK.”

I was pleased with how I responded: Gently, Kindly, and Considerately

Story 3 - Who Are You?

I expected the day to come, and it did indeed occur when Marsha asked:

Who are you? What are you doing here?

I had read and heard when some care partners tried to impress upon the fact that they were a husband or wife or mother or father, but this feedback only seemed to further agitate the person asking this question.

First, I told her I was her husband.

She replied that I was not her husband.

I then told her I was an old friend who has known her for a long time and that I didn't want to live by myself, so I am living with her.

She replied, "OK, I don't want to live by myself either"

Be prepared to respond to questions other care partners have heard from their loved ones. Don't make an emergency out of a natural emergence. Be prepared to respond in a calm, gentle, and perhaps humorous manner.

In fact, let me share a story about this experience from the book Travelers to Unimaginable Lands by Dasha Kiper

Story 3 - Who Are You?

(continued)

“One evening, as Sam helped his father get into bed, Mr. Kessler looked up and said in a kindly tone: ‘Who are you?’ Startled, Sam replied, ‘Your son.’

‘My son?’ Mr. Kessler said wonderingly. ‘How long have you been my son?’

‘Well, I guess sixty-two years now,’ Sam said, feeling both alarmed and amused.

Mr. Kessler’s eyes widened. ‘Sixty-two years you’ve been my son and only now you’re telling me?’

Sam laughed. ‘Well, sometimes it slips my mind.’

Seeing his son laugh caused Mr. Kessler to laugh as well.” (p. 17)

Story 4 – Doing Dishes

Experience

One afternoon I noticed Marsha at the kitchen sink taking some dirty dishes, running them through some cold water and placing them in the drying rack. I knew they were not being washed in a sanitary way ...

Pause/Process

.... I paused and remembered something Marsha said to me a few days before about my doing all the cooking and washing dishes and why couldn't she be doing some of that.

Respond

I thanked Marsha for doing the dishes and let her know how much I appreciated her helping out in the kitchen and how valuable her help was. I could tell she felt good about receiving this feedback. Later, when she was in another room, I took the still dirty dishes out of the drying rack, washed them in soapy water, rinsed them with hot water and then returned them to the drying rack. Later in the day she helped me put them away in the kitchen cabinets.

Reflection

I'm glad I paused before responding with how the dishes were not being washed in a sanitary way. Her wanting to help with dishes was the important focus. I gladly washed the dishes later.

Creative Writing

When I retired in 2021, I wanted to continue being creative with whatever came next after a successful career at CCSU as a university associate professor.

When Marsha received her diagnosis of “Mixed Dementia” that same year, I wondered if my goal to continue my writing would end . . . I was wrong!

My journal entries focused on my interactions with Marsha and I found my writing to be rich with creative possibilities.

Here is one example.

Interviewing Herbert the Hospital

As a participant in a writing workshop, we were asked to respond to the writing prompt - **BED**

As I thought about this writing prompt, I remembered a podcast from several years ago, *Everything is Alive*, in which inanimate objects were given a voice and responded to questions posed by an interviewer. I wondered what Marsha’s hospital bed might have to say to specific questions I might pose.

HerBert the Hospital Bed
(as interviewed by My Person's care partner)

What surprised you the most when you were assembled in our home?

I was given a place of honor in the living room where everyone could see me and see how important I was to provide My Person with support and comfort.

What's it like to hold a "dying person" with such a frail body?

I don't view My Person as a "dying person." They are a body who needs what I can provide them as they rest and participate in daily life with their loved ones. I feel privileged and honored to have been assigned this role of comfort and support. I live in the moment.

Were there some tense times between Your Person and her loved ones?

Yes, there were misunderstandings about how to respond to the reality within which My Person lived that differed from her loved ones' realities. But – when they saw the light and accepted My Person's new realities as their new realities, they got along splendidly.

Did you have any friends in Your Person's living room?

Yes, Mary, a sit-to-stand-recliner, was a constant presence and we know each other from the Medical Supply store where we both came from when Our Person entered hospice. We work as a team and Mary often lets me know what Our Person's support needs are after spending time with her during the day. Stan, my other good friend is a TV and he set such a pleasant atmosphere with a dash of light classical music in the background.

What is unique about you?

Well, I'm glad you asked that question. Unlike a stationary bed, I can bend my frame to enhance the posture of My Person as they rest or sit up depending on their needs. However, I can't press the controls that bend my frame. I must rely on My Person's loved ones to do that - - - but I am always at the ready!

Do you communicate with Your Person?

We don't use words to communicate. I am present to be of support and serve both the physical and spiritual entities of My Person. I don't need praise for the diligence of my support. It's what I do, but extra-long sheets and a clean exterior are most welcomed!

Any final words?

Thank you for asking me these questions. We are often underappreciated.

Creative Writing (continued)

A Reflection While Sitting on the Deck About Six Months After Marsha's Passing

I haven't been out on the deck by myself for quite some time. It's a very pleasant August day – my birthday eve to be exact. The day lilies are in bloom once again in the center of the backyard. There's a clear blue sky – slight breeze on occasion.

A butterfly comes over to inspect me as it sets about to sense the order of things. I must not be worth its interest. "What are you doing out here?" it might be thinking.

How long will I stay? It depends.

How long does it take to drink a large cup of Kona, whole bean, ground coffee?

Do the empty chairs talk to each other when no one is around? Are they jealous of the one I chose for my stay on the deck?

Well, that's the final sip.

"How long was I out here?" I wonder.

"I wasn't keeping time," replied my inner voice!

Creative Writing (continued)

Some Days ... And

Some days, you tell me you want to visit your mom;
And she died 12 years ago.

Some days, our daughters call;
And when you hang up you wonder who they are and where we know them from.

Some days, your friend calls on the phone;
And you wonder why you can't see her today since she sounds so close.

Some days, you buy food from the grocery store;
And when we get home, you wonder how they got in the grocery bags.

Some days, you ask me if I will ever leave you;
And the answer is always the same, "*Never!*"

Some days, you tell me where you want to go in the car on an outing;
And when we get there, you tell me that was not the place you meant.

Some day, I will look back on this point in my life
And thank you for making each day a blessed opportunity to share our love for each other.

In Conclusion . . .

With a nod to Paul Simon:

*Slow down, I'm moving too fast,
I got to make these moments last.
No need to hurry, no need to run.
The important things will still get done.*

With a nod to Kenny Rogers:

*Know when to hold back.
Know when not to talk again.
Know when to walk away.
Know when to count to ten.*

A Final Lesson To Leave With You

You do what you think/feel is right based on the information and resources you currently have and, when you have new information and more resources, you experience more success in your caring partnership with a loved one.

But most of all:

**Be Gentle
Be Kind
Be Considerate**