

On the Path of a Perfecting Care Partner

Perceptions Along the Way

Version 1

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Ex **P** eriences

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Introduction

I'm not suggesting that I have all the answers or that I have experienced everything someone else has. I'm a firm believer that everyone's life/spiritual journey is unique and personal, and I'm in no place to tell you what you have or have not experienced. However, I CAN tell you what I have experienced and learned, and I hope it is of use to someone out there. Ryan Miller

In my journaling of experiences as a care partner for my wife Marsha, I have compiled a set of perceptions that evolved during the adventure that Alzheimer's brought into our lives.

Since there is no such person as a "PERFECT" care partner, I gave a title to my journal entries: Perfecting the Care Partner Experience

What do I mean when I use the word PERCEPTIONS?

Here are some words that come to mind:

Experiences Thoughts Ideas
Feedback Reflections
Tips by Others
Ponderings Quotes
Suggestions Considerations
Insights

Introduction

(continued)

A perception is not a TRUTH!

I read a quote recently: There are no truths. There are only stories!

I'll share a few stories followed by some lessons I gained and how I formed new perceptions about my relationship with Marsha.

**But first what is a Dementia Positive Framework?
Note the following differences in approaching a common experience:**

**Instead of saying,
“You dropped some food on your lap.”
You could use different words,
“The food slipped off your spoon.”**

**Instead of saying,
“Your shoes are on the wrong feet!”
You could said,
“This shoe would be more comfortable on your other foot.”**

The language we use when describing interactions with a loved one living with dementia impacts the dignity of that person.

Dementia Positive language emphasizes dignity and respect in our interactions with loved ones.

Story 1: The Time is NOW!

In my experiences with Marsha, I learned that “waiting” was extremely difficult for her.

For example, at 8:00 in the morning I might make a comment that it was a good day for a trip to Goodwill. She would typically agree with much enthusiasm. Then I would say, “It doesn’t open until 9:00 so let’s WAIT for about half an hour so that we get there just when it opens.”

Without intending, I have now created a half hour of anxiety for Marsha who will make comments like:

- We are going to be late!**
- Someone will take something I wanted to buy!**
- We will never get there in time!**

What might I have done differently?

First, I could have waited until 8:30 to make the announcement about going to Goodwill and leave right away. But it might also be the day when I get stuck behind a school bus!

Or, we could have left shortly after 8:00, parked near the store, and joined the group of people also waiting for the doors to open.

I noticed that Marsha enjoyed listening to the people talking and being part of the “first group of shoppers” for the day.

Story 1: The Time is NOW! (continued)

My Lesson

When letting Marsha know about going some place, be prepared to leave RIGHT NOW!

Or

Bring some music to listen to in the car when waiting for a store to open.



Story 2: The Cost of a Date

Let's stay with the Goodwill theme.

One of the first areas of the store Marsha would go was to the pocketbooks.

She often found “just the right one” and put it in the cart.

I learned very early on that my unwanted comment, “You have enough pocketbooks at home.” would be met with an expression and words to convey - *what did I know about having too many pocketbooks.*

It took me several trips to Goodwill to realize that the total cost of most of her trips was around \$20.00 and she was very content with her purchases.

I thought – “She is at ease moving around the store, she makes purchases, we are having a good time, and I looked upon it as a date.

Story 2: The Cost of a Date (continued)

My Lesson

My whole perception of buying items at Goodwill changed. I could just give the items back at a future time. We could afford the \$20.00 and Marsha enjoyed reviewing her purchases when we got home and we found a place to put them.

Being with Marsha and enjoying our time together was more important than worrying about the minimal cost of buying “stuff” to bring home.



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.*

Story 3: Who Are You? (continued)

My Lesson

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.

“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: You're the One with Memory Issues)

Marsha would sometimes bring up a memory from the past that I wasn't sure happened or that I didn't remember the same way.

She would get frustrated that I had done something but didn't remember it.

At first, I tried to explain that it was OK to have different memories of the past and both of our memories could be right.

This did not go over well.

So, I tried a new approach.

Here is what I said:

I'm sorry about what happened, I will try not to do the same thing again. or

You have an excellent memory of what happened in earlier parts of our life. I wish I could remember things as well as you can. or

It was not right for me to have said that to you. Please forgive me.

My Lesson

Memories are not facts. I did not question something Marsha said happened in our past. I just focused on assuring her that I would try real hard not to allow that to happen again.

Story 5: My Husband is Looking for Me

One day, Marsha informed me that her husband was looking for her and was taking her back to Southern Illinois where her home is and where she is a teacher of young children.

I paused – took a few deep breaths and ...

... told her we could take a trip to some local spots where she thinks her husband might be and, if she sees him, we could talk to him.

The next day we drove to different parking lots at supermarkets and other stores.

We listened to music in the car and I would occasionally ask if a man leaving the store was her husband.

After about 15-20 minutes, I would say, “It doesn’t look like he is at this store. Let’s go home and try again tomorrow.”

**This routine occurred for about three days and then . . .
Marsha didn’t ask to go find her husband anymore.**

We did leave him a message on our home answering machine indicating where Marsha could be reached and I told Marsha this was his answering machine.

She accepted this and I felt OK with this method of getting in touch with him

Story 5: My Husband is Looking for Me

(continued)

My Lesson

I had heard the term – therapeutic lying. I didn't like the sound of it.

But it seemed to fit these circumstances. By leaving a message on our answering machine and telling Marsha that the message was on her husband's answering machine, this appeased her and she didn't mention him again.

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 Thought 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.