

On the Path of a Perfecting Care Partner

Perceptions Along the Way

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Ex **P** eriences

Id **E** as

Ponde **R** ings

Refle **C** tions

Fe **E** dback

Ti **P** s by Others

Sugges **T** ions

Ins **I** ghts

Qu **O** tes

Co **N** siderations

Thought **S**

This document contains the wisdom I continue to gain and reflect upon in my role as a care partner for my wife, Marsha. I refer to this wisdom as different “perceptions” I experienced in this unexpected role. I intend for the ingredients in this writing to expand as care partners read my entries and add their own perceptions based on their own unique experiences. Currently, I have divided my entries into the following categories:

- **Calm – Gentle Responses**
- **Communication**
- **Contented Involvement**
- **Expect the Unexpected**
- **Mindfulness**
- **Outside Supports**
- **Positive Perspective**
- **Time – Timing**

I didn’t know what word to use when referring to the person with a cognitive impairment receiving support from a care partner. I thought of words including loved one, relative, partner, spouse, friend, parent etc. They all seemed too impersonal. Accordingly, I will use Marsha’s name throughout this document. I also use the present tense in accumulating these perceptions as I wrote them during my active interactions with Marsha, who passed on March 22, 2025. Some of this content is also written as future advice for me to follow when I experience similar challenges.

***My desire is to know what I have lived,
that I may know how to live henceforth.***

Henry David Thoreau

Calm – Gentle Responses

- Be careful not to criticize Marsha for not complying with a request, but find a more creative way to achieve the same outcome.
- Be persistent in my love and caring.
- Currently volatile situations will soon pass. I need to look beyond the words Marsha uses to the essence of my relationship with her.
- Doing nothing is an apt response as in the expression attributed to Martin Gabel: *Don't just do something, stand there!*
- Drawing attention to an item that Marsha can access next may involve moving that item within closer proximity.
- Gentle approaches to a perceived action are not always the easiest approaches but, in the long run, are the right choices.
- It is often more effective when asking Marsha to complete a reluctant activity to precede it with a request that is likely to be responded to in a favorable manner. For example, at times Marsha may not initially take her medication. However, she is more likely to respond positively to this request if she first samples some of the fruit drink or beverage that goes along with the medicine.
- Mistakes are going to happen. How can I change my approach the next time a similar circumstance occurs?
- ... *(the) more distressed you are, the more distressed and behaviorally unpredictable the person with dementia will be.* (Pauline Boss, *Loving Someone with Dementia: How to Find Hope While Coping with Stress and Grief*)
- Play light, classical music in the background during times when “waiting” is difficult, like a repair person coming to the house.

Calm – Gentle Responses

(continued)

- Recasting can be a beneficial response; i.e., when Marsha refers to a member of the family and mentions a relationship that isn't true. I can recast that relationship in its true form, without sounding like I am correcting her perception.
- Reflect and study what happens on days filled with positive feelings and outcomes in order to better plan the sequence of events on future days.
- There's no limit to the number of hugs I can offer Marsha.
- When Marsha asks who I am and what I am doing in her house, I tell her I am a long-time friend who has been living with her so I wouldn't have to be alone.
- When other care partners experience a challenge, I try not to offer advice on what they should do. Instead, I offer a strategy that I tried that appeared to be successful.
- When Marsha misplaces something of value, I calmly react that something is missing and wonder where it may be. I don't place any blame.

Communication

- Avoid using phrases like “Try to remember” or “Don’t forget to _____.”
- Avoid using the word “no” in conversations with Marsha.
- Don’t argue facts.
Look beyond the facts.
- “I love you” can never be said too often in both words and gestures.
- “*I’m sorry*” is often the best response when Marsha tells me of an action from the past when she did not like how I acted. “*I’ll remember not to do that in the future*” is also not a bad response.
- Marsha is not a child in an adult body but an “adult” with a steadily changing brain and I should interact with her in an adult-to-adult manner.
- My tone of voice and body language often convey a far different message to Marsha than just my words.
- Negative sounding feedback can be restated in more positive terms; i.e., instead of “Your shoes are on the wrong feet” I can say, “This shoe would feel more comfortable on the other foot” and instead of “You spilled some food on your gown” I can say, “Some food fell off your spoon.”
- Setting the tone for the next positive interaction takes planning and insight.
- A statement like, “It’s time for _____” is preferred to a question, “Do you want to _____?”
- “Thank you” can be said several times a day so that Marsha knows how much she is loved and appreciated.

Communication

(continued)

- When I announce what I am going to do next, I extend an invitation for Marsha to join me.
- When providing feedback to other caregivers I can say:
 - In my experiences, I tried . . .*
 - A great resource I have discovered is . . .*
 - A strategy that seemed to work for me was*
 - ... Instead of ...*
 - You should do ...*

Contented Involvement

- Celebrate the small victories each day!
- During times of peaceful contentment, I can think back on the rocky road to get to this day and give myself a pat on the back for staying true to my values when interacting with Marsha.
- Even though it is easier to do things for Marsha, I try to see how much of an activity she can do with my partial assistance.
- Home is a Judgement Free Zone!
- I cannot “fix” Marsha. However, I can fix/change the environment to better meet her needs.
- It is better to wait outside a store 15 minutes before it opens than to spend that same 15 minutes at home amid anxiety and tension about making it to that store before it opens!
- Learning to live with imaginary people may be better than trying to explain away their existence.
- Moving from one activity to another is easier than initiating a new activity after a period of inactivity.

Contented Involvement

(continued)

- Plan the day so that there are at least seven activities that involve both of us in its completion.
- Recharge our batteries. Sit on the couch, hold hands and listen to some soothing music with Marsha.
- Routines increase contented involvement.
- Two requests that should always receive an immediate “yes”: *Will you help me with something? Will you sit down beside me?*
- When eating a meal, Marsha may be more comfortable with a small plate/bowl with food than a large plate/bowl with a great deal of food.
- When making a transition to a new activity, I give Marsha an item that will be needed in that new activity; i.e., a nightgown when it is time to get ready for bed.
- When Marsha approaches me with a need or request for help, there is often a much better outcome than if I initiated that same need/request.
- Working alongside Marsha is a better strategy than giving confusing directions about what to do; i.e., vacuuming (I use a second vacuum and clean side-by-side), cleaning the kitchen sink (each of us have some paper towels), making the bed (we are on opposite sides of the bed), etc.

Expected the Unexpected

- Be prepared to be interrupted. Put things down and go with the flow. Items on my to-do list can wait.
- Emotional highs and lows in our relationship will occur at unexpected times; however, the lows will typically be brief and run their course.
- Often, mood changes are unpredictable and unexpected.
- Small, momentary incidents can trigger a whole lot of unpleasant memories by Marsha.
- Sometimes you go looking for connections; while at other times, connections come looking for you.
- There are treasures buried within the many piles of stuff. I need to take time to uncover each one.
- There is always a significant challenge looming throughout each day; the name just keeps changing.
- There is an expression, “Expected the unexpected!” Just as important is an equally true expression, “Expect the expected!”
- Unexpected events can bring out competencies in Marsha that otherwise would not have surfaced.
- When all is said and done, there is always more to say and do!

Mindfulness

- Every morning starts with a clean slate. What happened yesterday is in the past and what will happen tomorrow is anyone's guess. Focus on the now.
- Forgive yourself for allowing fatigue and frustration to permit feeling sorry for your SELF. Contributed by G.S.
- Live in the moment.
- Marsha has gifts to share if I am a gift finder. (from the wisdom of John McKnight)
- Mysteries unfold each day if I stop, look and listen for their arrival.
- *(The) Opposite of a fact is a falsehood, but the opposite of one profound truth may very well be another profound truth.* (Niels Bohr)
- Outings can be important in and of themselves; the destination often doesn't matter.
- Practices of mindfulness may be enhanced by reading from the writings of Thích Nhất Hạnh.
- Take time to focus on my breathing.
- Tender moments are to be cherished.

Outside Supports

- My outside-the-home supports provided ways to help me access emotional outlets from being a care partner.
- Sometimes outside supports can cause greater stress than perceived benefits.
- When Marsha used a hospital bed during hospice, I placed it in the middle of the living room where she could have greater access to the daily pattern of meaningful activities.

Positive Perspectives

- All things are possible
Many things are probable
Some things are bound to happen
Nothing will change until I do!
- As I accompany Marsha to the room of her choice, I often find something that also needs my attention in that room.
- Destinations may not be the real goals; spending quality time with Marsha takes precedence.
- Emergences are an unfolding of events to be expected. Even though there is only one letter added, I need to plan for emergences to avoid emergencies.
- Every day is a new experiment.
- If I only followed my own advice, things would run more smoothly throughout each day!
- It is difficult not to take personally harsh words Marsha may direct at me.
- It's a new day – enough said! There is an impermanence to success. What worked well one day may never work again and what did not work today may, in fact, be just the right strategy tomorrow.
- Keeping a journal of perceptions, reactions, thoughts, opinions etc. allows me to reflect on experiences and put them in their proper perspective.
- Maintaining a sense of humor helps me to view a daily idiosyncrasy in a new light.
- My story/journey is my story/journey. It is worth remembering but it is not the story/journey of anyone else.
- Names of stores/places didn't register with Marsha as much as what may have happened in those stores/places.
- Normal! Perhaps normal is just a myth to begin with!

Positive Perspectives

(continued)

- Rather than, “I don’t have time for _____,” a more accurate statement is “I don’t take the time for _____.”
- React to stories from the past, even though I have heard them many times, as if this is the first time.
- Realizing what to do next is often determined by my set of values and truths rather than what is right or wrong to do.
- Taking responsibility to be wrong and mistaken following Marsha’s comments about what has occurred in the past is not always easy to do . . . but it certainly is necessary.
- There is no right versus wrong in our memories. Past events are only perceptions of what we believe to be true that are not worth arguing about.
- There will always be something missing. I need not panic but just realize that I will find each item at unexpected times in the future.
- Truths are reminders of the relationship I have with Marsha. I don’t have THE TRUTH but, together, we share our “truths.”
- We are more alike than different.
- *We both have different memories of our past and we are both right to respect each other’s memories. ELP*
- What I am learning about myself is equally as important as what I do each day as a care partner with Marsha.
- When a significant memory is forgotten it doesn’t mean it didn’t happen. I don’t need to argue about it.
- When evaluating what course of action to take on any given day, I think to myself, “*What would I say about this activity 10 years from now?*”

Positive Perspectives

(continued)

- When giving Marsha a specific request, the network of connections in her brain for receiving, interpreting and responding to that request may be interrupted. That doesn't mean she cannot physically complete the request.
- When I hear words of anger, I realize Marsha is experiencing anguish!
- When Marsha is confused about her relationship with a family member, I let it be.
- When Marsha leaves items in unusual places, I look at it as an opportunity for more exercise in putting items back in their respective places.
- When reacting to a stressful situation I think "Is what I'm about to say going to escalate this tension further?" before responding. Sometimes, doing nothing is more important than reacting in an emotionally driven manner.

Time - Timing

- Next Thursday, Friday or Saturday may all mean the same. The only reality is right now! There is no "later" in Marsha's sense of time!
- *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.*
- Timing may not be everything, but it is something that must be fine-tuned each day.
- With apologies 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.*