

# On the Path of the Perfecting Caregiver

## Lessons Learned From a Caregiver's Perspective

Ernest L. Pancsofar

I am adopting a new format to a previous edition of *Lessons Learned* by framing each lesson in the following four questions:

**E = What is the Experience?**

**P = Pause/Process** - what is the essence of what is happening?

**R = How can I respond** in the gentlest manner taking the processing step into account?

**R = What brief reflection** can summarize my learning?

Each **experience** on the following pages is an event that occurred spontaneously between Marsha and me that presented a challenge for how I should/could best respond.

As each experience unfolded, I **paused** built in a “wait time” to understand what was going on and **processed** what approaches to try next in my role as caregiver.

When I did **respond**, I wanted my reaction to be the gentlest way I could enter into the challenge given my past experiences and current feeling of what to do.

Finally, after I captured the learning moment in my daily journaling practice, I developed a very brief **reflection**; not always right away.

# Lessons Learned

## (The EPRR Approach)

### Experience

After arriving back home from a brief trip in the car, Marsha told me she was not going in the house.

### Pause/Process

I decided this was not an emergency and tugging on her 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 for her to go in the house. After 5 minutes, I got out and invited her to join me in the house.

After another 5 minutes elapsed ...

### Respond

I poured a drink of juice, went out to the car and gave it to Marsha with the words, "Bring this glass back in the house when you're 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!

### Reflection

There's more than one way.

## **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.**

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**When Marsha was eating her oatmeal for breakfast, she liked to scrape the spoon in the bowl to get the last possible bit of oatmeal, and even then, continue to scrape the bowl some more. It was now time for her to take her daily medicines, which I had crushed up and placed in some applesauce. However, she would not let go of the now empty bowl of oatmeal and let me exchange it with the small bowl of applesauce.**

### **Pause/Process**

**After about 5 minutes I sat down beside her and held the small container of applesauce in my hand and inched it closer to her line of vision. As I was doing this, I was completing my slow breathing practice for 15 breaths during which I thought of my next approach.**

### **Respond**

**Since Marsha was already engaged in scraping her now empty bowl of oatmeal, I transferred the applesauce that contained her medicines from its small container into the bowl that had contained the oatmeal. She readily accepted this and then began spooning the applesauce into her mouth and I had SUCCESS.**

### **Reflection**

**Incorporating a new request within an existing activity can result in a positive outcome.**

***I had a conversation with Marsha today  
I asked her to listen carefully to what I had to say.  
“I think you know some changes are happening to  
you  
And that I will always be here to see you through.  
We are in this life together - - - I will always be there  
To support, comfort and provide you with my loving  
care.  
You talk with your eyes and the way you squeeze my  
hand.  
I can sense your love and I think that’s just grand!”  
After I was through talking to Marsha, I heard her  
whisper,  
“Be careful,” as I went on my way. ELP***

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**Marsha and I enjoyed going grocery shopping together --- most times. On occasion, she would select an item to put into the cart that I suspected she would not eat nor even liked. I found that when I brought this to her attention, it would be a trigger for feedback about how she can make those decisions, and I should not interfere.**

### **Pause/Process**

**I came to the realization that commenting on what Marsha put into the grocery cart was often followed by a rather negative reaction and defeated the whole purpose of going out and doing something together. I thought about what a dinner out might cost if we were on a date. In essence going grocery shopping was a event she found quite enjoyable.**

### **Respond**

**I stopped commenting on what she put in the cart and, on occasion, I was quick enough to put some items back without her noticing. I realized that the amount of money these items cost rarely totaled more than \$20.00. To offset this waste, I started making a monthly donation to the Covenant Food Kitchen in a nearby town.**

### **Reflection**

**What is the “real” reason for community outings? Being together with Marsha and completing an activity together could result in a satisfying experience, if I only kept this in mind.**

# **Processing the Loss of a Loved One**

**First, it's a life-time experience  
Of memories, the order of which, jumbles in my mind.  
There is no "getting over it"  
When missing a one-of-a-kind.**

**The solitude can be both welcoming and bring sadness  
When I don't see you on the other side of the room.  
The silence allows for fewer distractions  
And can even lessen some of the gloom.**

**You had a rough journey  
Held in dementia's grip.  
Yet, you were always graceful  
On this unexpected trip.**

**I learned a great deal  
By being by your side.  
When my time comes a callin'  
Please come back to be my guide.**

**Time passes by  
In oh so many ways.  
I'm glad I was here to witness  
The closing of your days.**

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**When Marsha was ready to go somewhere, she wanted to go “right now!” At first, I would tell her the store was not open yet and we needed to wait awhile before we headed out. This was not a well received answer. She became quite anxious and on the way to the store would comment about missing out on important items because we were going to be late.**

### **Pause/Process**

**After two frustrating experiences of waiting with Marsha at home when a store was not yet open, I looked for a better solution that would more likely result in a pleasant outing.**

### **Respond**

**Waiting at home enhances a sense of anxiety and frustration by Marsha. However, waiting in the parking lot or among the queue of people awaiting the store’s opening, did not produce the anxiety or frustration from previous outings. And, she seemed quite content waiting among shoppers and listening to their conversation.**

### **Reflection**

**Marsha’s sense of time was making it difficult to distinguish how much longer “later” meant. Waiting outside a store produced much more positive outcomes than insisting on staying home and leaving “later” to arrive at the store close to its scheduled opening.**

## Responding 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.

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### HerBert the Hospital Bed (as interviewed by My Person's caregiver)

**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.**

## **Lessons Learned (The EPRR Approach)**

### **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.**

**Welcome to any day;  
Closely related to some day;  
A lot like every day;  
And yet like no day.**

**Anything might happen;  
Something is bound to happen;  
Everything in its own time;  
Nothing is certain.**

**Good events could happen anywhere;  
They are certainly happening somewhere;  
There are common events everywhere;  
The exact events will happen nowhere.**

**Dementia can happen to anyone;  
Dementia will happen to someone;  
The future of Dementia needs everyone;  
The effects of Dementia will escape no one.**

**Any place can claim to be a good place;  
Some places are actually good places;  
Every place can't be THE best place;  
No place is like home, which could be the best place.**

**Anybody could be a caregiver;  
Somebody must be a caregiver;  
Everybody should support caregivers;  
Nobody can replace a loved one as a primary caregiver.**

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**On one occasion as Marsha and I got settled into the car, I remarked, “Put your seatbelt on.” She replied, “You never told me I had to wear a seatbelt.” ...**

### **Pause/Process**

**.... In Marsha’s mind, I had never previously told her to wear a seatbelt and I did not want to be insensitive and explain that everyone had to wear one.**

### **Respond**

**I apologized for not letting her know until now that a seatbelt was required of the driver and all passengers. I said I was sorry not to have let her know that until now.**

### **Reflection**

**In previous experiences I might have told her that it was the law that the driver and all passengers must wear a seatbelt. However, it was much more productive to apologize and say it was my fault for not bringing this law to her attention.**

## A Moment in Time

*I had prepared a blueberry muffin for Marsha and she ate it at 6:00 PM. Twenty minutes later she asked for a blueberry muffin and I said, “Didn’t you have one earlier?” “No,” she replied. “Fine, I’ll get one ready for you. If you get too full, we can save the rest for tomorrow.”*

*Last year I would have spent time trying to explain to Marsha that she already had a muffin and that she just forgot. That would have been a trigger for the rest of the night for a very unpleasant end to the day.*

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**While walking into the kitchen, I noticed that Marsha had removed a frozen chicken breast from the freezer and placed it on the counter to thaw ...**

### **Pause/Process**

**.... I didn't pause and I didn't process. ...**

### **Respond**

**I mentioned to Marsha that placing a chicken breast out on the counter was not a healthy way of thawing it out. Before I could suggest an alternative, she responded that she had been cooking for many years and knew how to cook and then left the kitchen quite upset with me.**

### **Reflection**

**Sometimes instinctively responding to a loved one with dementia results in a less than desirable outcome. I could have said, “Can I help by getting a container of warm water to help thaw out the chicken breast?” or “I just realized we have a defrost setting on our microwave. Let’s try it out on the frozen chicken breast.”**

**Mistakes can still be valuable lessons for future experiences!**

**Making mistakes is all part of living  
In doing so we are giving  
Others our own personal history  
Filled with growth and mystery.**

**Waiting for something to happen  
Can, itself, be a critical time in  
Which we prepare for where  
To go from here to there.**

**Embracing uncertainty can be fun.  
It's not really the work to be done,  
But the way in which we move about  
Amid the chaos and the doubt.**

**There is no future that is obvious to me  
So I'll just have to let it be  
And stay in the moment and see  
What will be a next opportunity.**

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**Marsha informs me that her husband is looking for her and wants to take her back to Southern Illinois where her family is.**

### **Pause/Process**

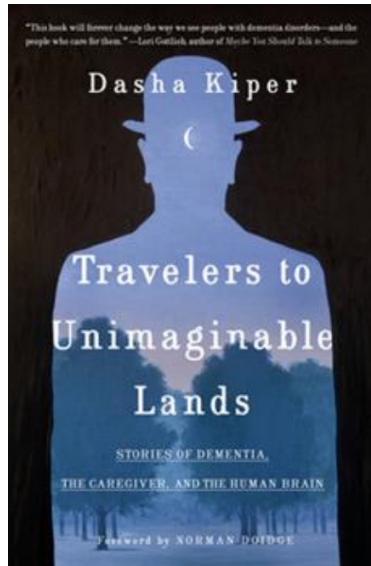
**There are temporary lapses in who Marsha thinks I am in her life. She tells me that I am not her husband. I don't refute her statement but let her know I am someone who has been a friend for many years and currently live in this house with her. Now, what to do when she wants to go find him in the local community because he is looking for her and doesn't know where she is.**

### **Respond**

**“Let’s go look for him,” I say. We go to different parking lots and I say to Marsha, “Look at the people who go in and out of the store” (grocery store, fast-food place, etc.). Let me know if you see your husband.” This went on for three different locations without spotting anyone she identified as her husband. “We didn’t find him today,” I said. “Let’s try again tomorrow.” “OK,” she replied. We did go out again the next day and the next. On the fourth day she didn’t request to go find him.**

### **Reflection**

**Go with the flow. Accept the realities as envisioned by a loved one, as long as no harm is foreseen. Enjoy each other’s company.**



I chuckled at the following account as I encounter a slightly different version when Marsha asks, “*Why didn’t you tell me about my appointment with Dr. C\_\_\_\_\_?*” or a similar future event.

“*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)

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**“There’s a man staring at me through the window!” Marsha said to me with anxiety in her voice. I went to the window and said, ”There is no one there.”**

### **Pause/Process**

**My response to Marsha’s anxious assertion did not adequately respond to her feelings of unease. After this experience, I wondered how I could validate her pending unease without adding undue fear to her delusion.**

### **Respond**

**I could have said, “He’s gone. That must have been a frightening experience. I can order some black out curtains so that anyone outside can not see inside our bedroom.” I did find myself using a generic approach when a similar issue occurred. I would tell Marsha I would investigate and thanked her for bringing her concern to my attention. Then, I would give her the all clear and say, “They are gone now. They must have heard me coming. Come have a look.”**

### **Reflection**

**Marsha isn’t panicked when she senses someone is in the house or outside. I believe she just wants a reassurance that everything is OK now after I have investigated. Haven’t we all heard noises in the house and the clanging of pipes and shifting of parts of the house?**

I found the following quote in a book I am currently reading and it represents a perspective I hold to be true:

*Caregiving can narrow your field of vision in the day-to-day, but a grander sense of perspective will also take shape. You might come to see just how long the list is of things not to worry about: the pettiness of office politics; the nightly news; the traffic. Now you might find yourself more moved by silence or morning birds or small signs of kindness. You care, you show up, you face reality with someone, you touch the limits, and maybe you learn something about yourself.* In BJ Miller and Shoshana Berger, *A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death.*

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**Marsha would comment, “You don’t remember the past as well as I do. I think you’re the one with a memory challenge.”**

### **Pause/Process**

**It is not unusual for a person experiencing dementia to have a much better long-term memory than to remember what happened yesterday. At first, I tried an approach in which I said to Marsha, “We each have different memories of the past and that’s OK. Both of our memories are true as much as we remember.” This “reasoning” did not go over well and I had to realize that as far as Marsha was concerned, her version of what occurred 20 years ago was correct and I was wrong.**

### **Respond**

**I started to respond with a general statement: “I don’t remember the experience you are mentioning. However, your memory of what happened earlier in our time together is probably quite accurate. I’m sorry I said those things to you or did something that upset you. I will try real hard not to do that again.”**

### **Reflection**

**My response of acknowledging Marsha’s memory of an event from long ago as the “true” version of events worked quite well. My apologies for not responding in a way Marsha thought was right were accepted and we continued on with what we were doing. I don’t need to have my memory of past events flavor the atmosphere of the current moment.**

# Drinking Coffee on the Deck

**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!**

## **Lessons Learned (The EPRR Approach)**

### **Experience**

**The words we use can be expressed in a negative or neutral context.**

### **Pause/Process**

**I need to be careful when I interact with Marsha to phrase a comment in a positive frame of reference.**

### **Respond**

**I say, “Food slipped off your spoon,” rather than “You dropped food on your shirt.”**

**I say, “That shoe may be more comfortable on the other foot,” rather than “Your shoe is on the wrong foot.”**

**I say, “I’m going to brush my hair, do you want to join me?” rather than, “Your hair needs to be brushed.”**

### **Reflection**

**Pausing before commenting on an activity/event allows me time to phrase my feedback in a more positive light.**

# More Truths I Have Discovered

**Recharge your batteries. Sit on the couch, hold hands and listen to some soothing music with your loved one.**

**The names of stores/places don't register as much as what may have happened in those stores/places.**

**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.***

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

**A mystery unfolds each day if I stop, look and listen for its arrival.**