The background is an abstract composition of organic, cellular-like patterns in various shades of blue and green. A prominent black crosshair, consisting of a vertical and a horizontal line, is centered over the image, creating a grid-like structure that divides the organic patterns into four quadrants.

# The Emotional *Impact* of Caregiving

Barbara Hemphill, MPS

# The Emotional Impact of Caregiving

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2019

# Who is driving your emotional life?

Figure 1

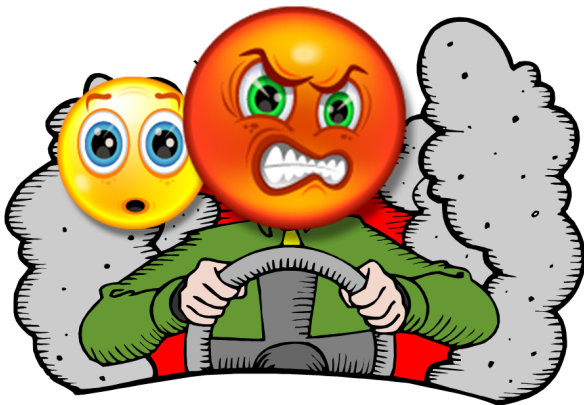


Figure 2



Do you feel driven around by your anger, anxiety, sadness, or guilt ... as if you are only a fearful passenger? (Figure 1) You want to let go of the painful feeling, but it seems to stick to you like a sheet of self-sealing plastic wrap? Do you feel like emotional flypaper? If this describes your emotional life as a caregiver, with a little exaggeration perhaps, then you may find hope in this booklet.

The ideas presented here are designed to help you move back into the driver's seat (Figure 2). With these techniques, the painful emotion begins to function more like a back-seat driver — it remains in the car, it can still shout directions at you, but you decide whether to listen to its message. The emotion's power over your life is greatly reduced.

# Four Keys to regaining the Driver's Seat

## 1) Normalize the experience of painful emotions.

We will consider why negative emotions are so common and so powerful in caregiving.

## 2) Analyze your emotional response.

In order to think about how you are feeling, you must step away from the emotion just a bit. In doing so, you create a little psychological distance between *you* (the one who feels the emotion) and the emotional experience itself. It is in that little gap that you begin to experience yourself as the driver, rather than the passenger. You are not your emotions; you are the one who experiences them. This is one small step for a man, but a giant leap for peace of mind. We will look at simple ways to think about feelings, so you can develop this practice.

## 3) Employ techniques that are proven to reduce stress & increase emotional resilience.

There are many such practices. This booklet includes a list of a few that you can fit into your time-challenged life.

## 4) Change the story of your pain.

Unfortunately, caregivers often face painful situations which they cannot change. When you cannot change the situation, you may be able to change the story you are telling yourself about it and thereby reduce your emotional pain. If you practice keys 1-3, you will create a climate conducive to changing your story. We will examine the typical elements of the stories we tell ourselves and see how to find ways to change them.

# Categories of painful emotions



**Angry**



**Afraid**



**Sad**



**Guilty**

Figure 3

To keep things simple, we will look at these four categories of painful emotions. **Angry** feelings can be anything from simple annoyance to rage. **Sad** feelings can be anything on the continuum from feeling blue to depression. **Afraid** can represent anything from anxiety to terror. And well, **Guilty** is that feeling we all know. It is a category unto itself.

The point is that the emotions within each category have some commonalities that allow us to view them through the same lens. See the Appendix (page 23) for one example of this categorization method.

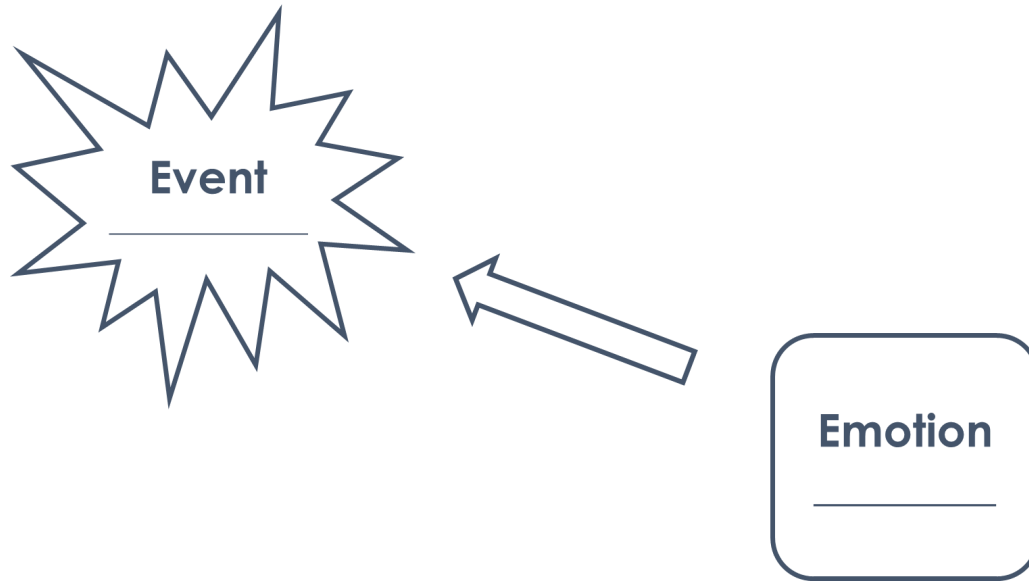


Figure 4

Let's begin with a simple exercise that will help you to integrate the lessons in this booklet.

In the diagram above, under "Emotion" write a feeling you struggle with, either now or in the past. Hopefully the emotion you record fits into one of the categories in Figure 3. It will help to remember the category too, so you might note that as well.

Under "Event" write a word or phrase to name a situation which commonly evokes this emotion in you.

# Key #1: Normalize the experience of painful emotions

A 2015 survey of U.S. caregivers indicates that the life changes shown in Figure 5 are very common in caregiving. These changes are synergistic — a change in one area affects other areas as well, and their combined effect is greater than the sum of their separate effects. This can create a spiral of painful emotions.

In the survey, 60 percent reported making some kind of change in *employment* — cutting back on hours, working more from home, changing jobs, quitting work, retiring — in order to continue caregiving. If you reduce work hours, you earn less money. That directly affects your *financial status*. It may also affect your *self-esteem*, the ability to pay for social *activities* or medications (and so affect your *health*). These changes can result in anxiety, resentment, fear, and guilt.

In the same survey, caregivers reported an average 27 percent reduction in *activities* they had formerly enjoyed. When social activities are reduced, your *support system* takes a hit. *Relationships* can become more distant. Loneliness and sadness may result.

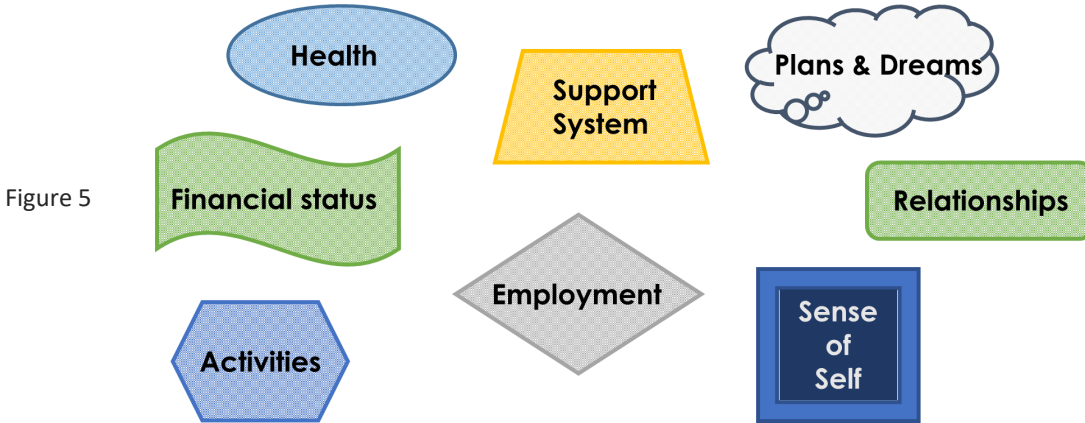
Thirty percent of long-term caregivers reported a decline in their own *health* while caregiving, due to both stress and their focus on their loved one's health. (This is likely under-reported because many caregivers are not aware of their declining health until after their caregiving ends.) The caregiver's doctor appointments and medications may be overlooked or postponed. In addition, dementia caregivers lose sleep when the person with dementia becomes confused about time and stays awake at night. Sleep deprivation adds to stress and reduces emotional resilience.

Caregivers reported significant changes in their *support system*. Often the person they are caring for was an integral part of the caregiver's support system. Now that support goes only one way. In addition, it is common for family members and friends to step back and decline to help. They may even become critical of the caregiver's decisions. The caregiver may feel lonely, angry, anxious as her support declines.

Often caregivers must give up on *plans and dreams* they have worked toward for many years. For example, a retirement home in the country or a trip to a bucket-list destination may become impossible because of health challenges.



# Caregivers' Life Changes



Of course, the most painful change a caregiver experiences is the gradual loss of *relationship* with the person they are caring for. Especially in dementia caregiving, watching the person you love virtually disappear one day at a time may be the most heart-wrenching event you will ever know. You really can't put an adequate label on that pain.

Facing these common life changes and challenges, is it any surprise that caregivers find themselves embedded in a sticky web of painful emotions? When we consider emotional **triggers** (in the next section on Key #2), you will see why these life changes have such potential to set off storms of emotional pain.

Key #1 is to remember that, because of all these changes and losses, feeling stuck in anger, sadness, fear, and guilt is just part of the caregiving journey. It is normal to feel this way.





# Key #2: Analyze your emotional response

We will look at two simple models, two ways of thinking about emotions.

- Emotion Triggers (pages 10-14)
- Emotions as Survival Tools (pages 15-17)

Each of these models offers a unique way to inwardly step away from a feeling and shift into thinking about it, by merely asking a question or two. When you find yourself experiencing a negative emotion, you can use one of these models to shift into analysis.

This can be especially helpful when you feel stuck in an emotion that just won't let you go, or if you find yourself mentally re-visiting a situation that is painful to you. This type of memory replay may embed you more deeply in the pain, so focusing on something else can help you break free.

The shift from experiencing the emotion to analyzing it is like moving from *reading* a good novel to *reporting* about it. When you are reading the novel, you feel immersed in the story. You may visualize the characters, hear their voices in your mind as you read. You may feel like an observer or a character in the novel. But when someone in your book club asks what you *think* of the book, you must shift out of the story and become an outside observer. The experience of immersion disappears.

Similarly, when you begin to analyze your emotional response, the experience of being immersed in the emotion fades. You feel more in control.

# Emotion Triggers



**Anger** motivates action to overcome the threat of perceived injustice



**Fear** ignites a “fight or flight” response to perceived danger



**Sadness** slows and dampens one’s ability to function, in response to perceived loss



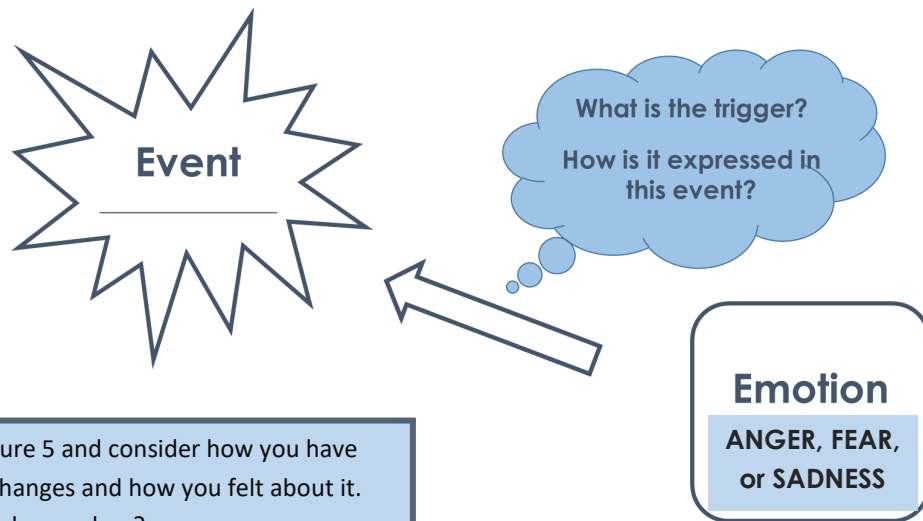
**Guilt** moves us to act with integrity, perceiving a behavior-values conflict.

Figure 6

According to this model, if you are feeling an emotion in the **Anger** category, then you are perceiving *injustice* in the situation to which you are responding. Likewise, if you are feeling an emotion in the **Fear** category, you are perceiving *danger*. And so on. The most common trigger for **Sad** feelings is *loss*. And **Guilt** is triggered by a perceived *conflict between your behavior and your values*.

To analyze your emotional response, ask how the trigger for that emotion is expressed in the situation. For example, if you feel **angry**, “Where am I seeing *injustice* or unfairness in this event?” Asking the question is even more important than finding an answer, because asking makes you step away from the feeling and create that critical gap between you and the emotion itself.

Figure 7



As an exercise, look back at Figure 5 and consider how you have experienced one of those life changes and how you felt about it. Did you perceive in it injustice, danger, loss?

These questions can be helpful with anger, fear, or sadness, but **guilt** is a little different from the others. It is focused on your values and how your behavior violates those values. Caregivers experience plenty of guilt, and I believe there are two reasons for that, illustrated in Figure 8.

First, caregivers bring unrealistic *expectations* into caregiving. You developed expectations of yourself, of your care partner, of caregiving, when you didn't have an accurate picture of the responsibilities you would be taking on. You conceived them when you were young and strong. By the time you become a caregiver, you may be much older, less energetic, perhaps even frail yourself. Those expectations just don't fit well in your caregiving universe, but you don't question them. You measure yourself by them and judge yourself guilty for falling short.

Second, guilt is about *values*, and unlike in ordinary life, in the caregiving universe your most deeply held values will often conflict with each other. This creates a dilemma. The caregiver must choose to honor one value and violate another. No matter which value you choose to honor, you will feel guilty for violating the other one.

For example, we value **autonomy**. We want to allow people to make their own decisions and have power over their own lives. We also value **"do no harm."** We want to protect ourselves and other people, including the person we are caring for. These two values commonly conflict in dementia caregiving. For the sake of safety, caregivers must prevent their loved one from driving, or move them against their will into assisted living. This violates their *autonomy*. But unless the caregiver is willing to make these choices, it is likely that *harm* will result. The caregiver must violate autonomy for the sake of doing no harm. She ends up feeling guilty for taking away her loved one's autonomy.

We value **honesty**, telling the truth. We also value **"do good."** These values also frequently conflict. For example, people with dementia ask about family members who died long ago, "Where is \_\_\_\_?" If telling them that the person passed away years ago sends them into grief, then for the sake of doing good, it's probably better to give up on telling the truth. Instead, a caregiver may use a "therapeutic lie" and offer some calming reason why the person is not here right now. The therapeutic lie may not be the ideal way to deal with situations like this, but sometimes it's all you have in your pocket at that moment. You pull out whatever tool you can use to do good. But you probably feel guilty for lying.

These diagrams illustrate the difference between ordinary life and the caregiving universe, in terms of values and expectations. In ordinary life, clear expectations are developed that begin to wobble when carried into the caregiving universe. In ordinary life, deeply held values tend to point in the same direction, but in caregiving they often conflict, leaving the caregiver feeling guilty no matter which value she chooses to honor. When values are at cross-purposes, a difficult choice must be made, and guilt lies waiting at the crossroads.

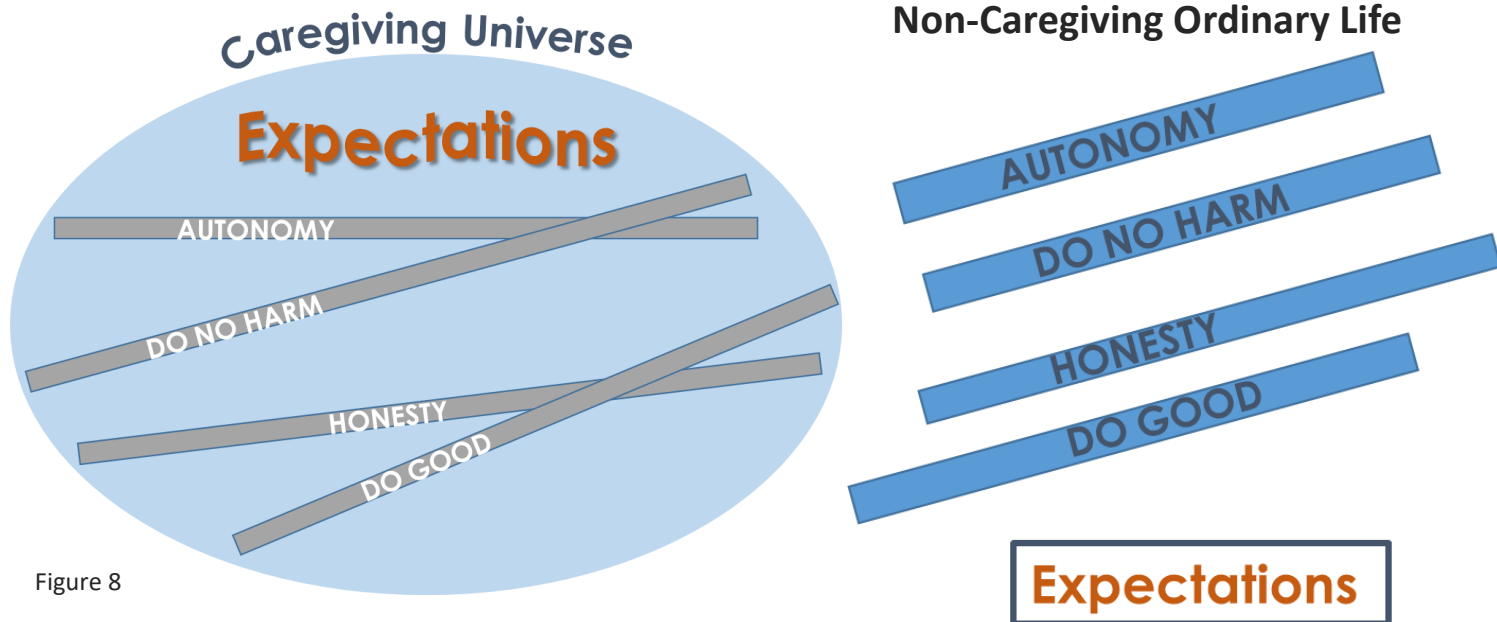


Figure 8

The “emotion triggers” model says that if you are feeling **guilty**, then you are perceiving a conflict between your behavior and a deeply held value. But it is important to recognize that there is probably another conflict in the situation — a conflict between two competing values, both of which are important to you.

Recognizing this values conflict opens a different line of questioning you can use to analyze your sense of guilt, and so to step out of it for a moment. You can ask which values are conflicting in the situation you are facing, and which value you are choosing to honor. These questions move you mentally away from self-blame, which sees only your violation of some value. As you focus on the values that are at cross-purposes, you remind yourself of your intention to act consistently with your values.

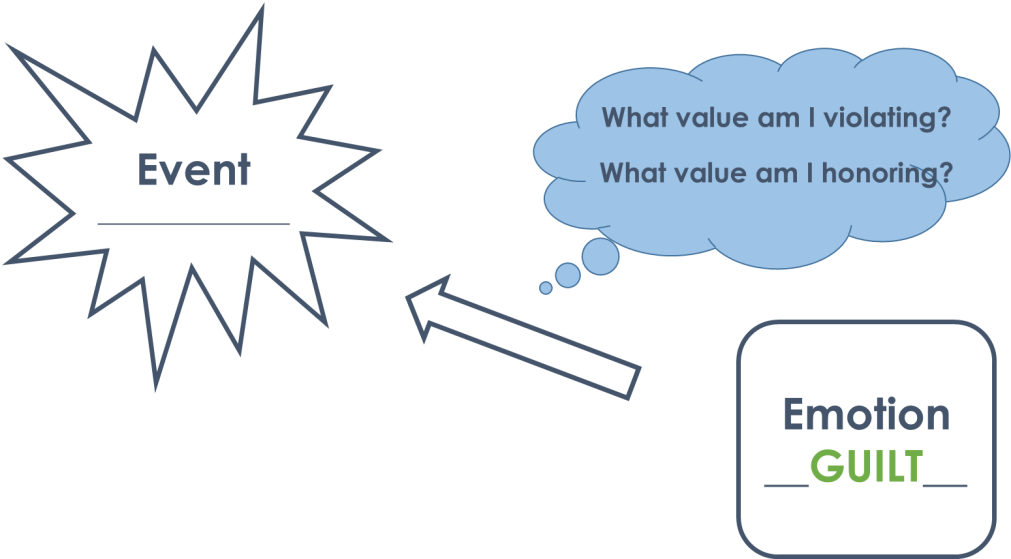


Figure 9



# Emotions as Survival Tools

“Negative Emotions” help us to protect ourselves and what we love from perceived threats



“Positive Emotions” help us to approach and welcome perceived opportunities

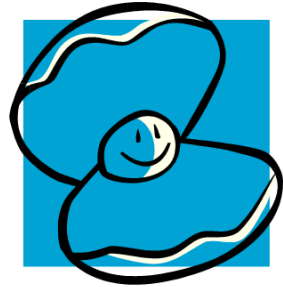


Figure 10

## Emotions as Survival Tools

This second model says that emotions serve a survival purpose. Human beings have experienced emotions since the beginning of our existence as a species, so they must be helping us thrive.

Positive emotions, feelings that we enjoy, help us to welcome and embrace situations that we perceive are beneficial to us. When we are happy, we open our arms like an open clam shell (“happy as a clam”) to embrace what is before us.

Negative emotions, feelings that hurt, help us to resist or run away from situations we perceive are threatening to us, or to something we value. “Fight, flight, or freeze” kicks in. Inwardly or outwardly, we clench our fists, ready for a fight. Or we cower and wrap our arms tight to protect ourselves. It’s all about protecting or defending what we love.

Simply put, this model says that negative emotions are part of a physiological defense system. The beauty of seeing your pain this way is that it becomes easy to shift into analysis. You don’t even need to know what the emotion is about. Any time you find yourself feeling irritated, anxious, sad, or guilty, you can acknowledge that on some level you must be perceiving a threat. Then ask yourself, **“What is threatened here?” or “What is at risk?”**

With this question, you acknowledge the presence of a defense mechanism. Your emotions are trying to protect you or something you value. Just realizing that will lessen your resistance to the emotion and help you to feel more in control.

When you ask these questions, you shift your attention away from the emotion itself and toward its protective purpose. You step out of the feeling and into thinking. As you have already seen, this little step is a very important one. By asking, you create that gap between you and the emotion. You are moving into the driver’s seat.

Taking a moment to ask the question is actually more important than finding an answer to the question. However, if you can find an answer and identify the perceived threat, then you may be able to change the situation and eliminate or reduce the threat.

These questions can be used with any painful emotion, even when you can't identify the emotional category. It doesn't matter whether you would name it anger, sadness, fear, guilt, or anything else. If it feels bad to you, you are probably sensing a threat, thinking that something or someone you love is at risk. The life changes in Figure 5 and the explanation on pages 6-7 offer helpful examples of the types of threat you may be perceiving.

This model of negative emotions as protective makes it even more obvious that the caregiver's role is naturally fraught with painful emotions, since caregivers are constantly living with protective responsibilities.

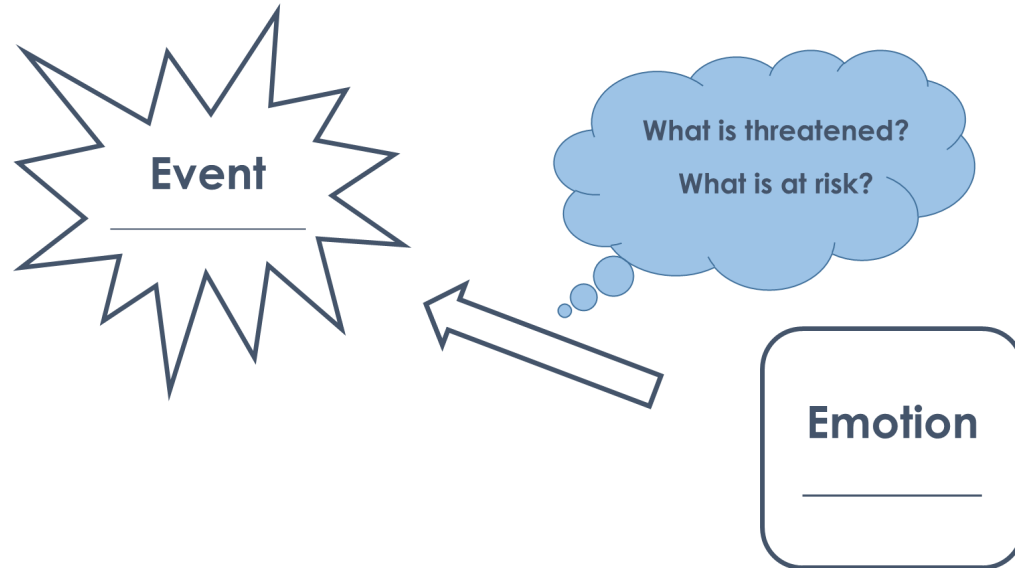
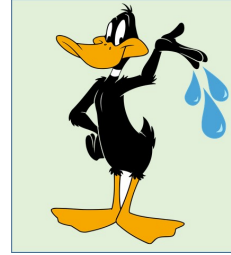


Figure 11

# Key #3: Practice techniques that build resilience



**from “emotional flypaper” to “water off a duck’s back”**

Emotional resilience is the ability to bounce back from painful situations, to quickly recover one’s equanimity. This involves both the ability to *experience* negative emotions (not resist them or deny them) and the ability to *let them go* after they have accomplished their purpose (see Figures 6 and 10). Caregivers often lose their resilience and find it increasingly difficult to recover from crises, especially when their responsibilities are carried on for many years.

As I said in the introduction, you can begin to feel like emotional flypaper. You just can’t shake off the sadness or resentment, no matter how hard you try. The *letting go* of resilience is neither as fast nor as superficial as “water off a duck’s back” implies, but when you have felt like flypaper, by comparison, it can seem pretty close to that.

The foundation of emotional resilience is composed of four principal factors — exercise, diet, sleep, and supportive socializing. If you regularly go to the gym, avoid empty carbohydrates and eat healthful food, get enough deep sleep, and spend time with people and activities you enjoy, you will probably be resilient. Unfortunately, for most caregivers, the life changes in Figure 5 translate into severe challenges in each of these four areas. That’s the bad news.

But there is good news. There are simple practices that have been shown in research studies to reduce anxiety, elevate mood, lower blood pressure, facilitate more efficient sleep, improve immune function, increase alertness, or enhance a sense of calm in a crisis. In short, they improve factors that build emotional resilience. Here are a few such practices, with links to the research.

Exercise — Try the four-minute workout, ideally done three times daily.

(<https://fitness.mercola.com/sites/fitness/archive/2017/11/03/4-minute-daily-workout.aspx> )

Gratitude — Spend a few minutes each day focusing on something for which you are grateful.

([https://health.ucdavis.edu/medicalcenter/features/2015-2016/11/20151125\\_gratitude.html](https://health.ucdavis.edu/medicalcenter/features/2015-2016/11/20151125_gratitude.html))

Meditation — Take a few minutes to sit in silence each day using any meditation technique you choose.

(<https://www.healthline.com/nutrition/12-benefits-of-meditation>)

Prayer — If you have an established habit of daily prayer, you may need to modify it to fit your time constraints.

(<https://www.healthfitnessrevolution.com/top-10-health-benefits-praying/>)

“Today I bless ...” combines prayer and gratitude into one practice. (<https://synapsesite.net/blessing>)

Breathe — When you feel anxious, take a few deep calming breaths — in through your nose, out through pursed lips.

(<https://www.anxieties.com/57/panic-step4#.XOI-6lhKg2w> )

Express — Find a creative outlet for your emotions — walk, dance, sing, paint, sketch, journal, write poetry, play an instrument. Talk about your feelings with a supportive listener. Join a support group.

Plan Joy — Plan something you can look forward to. Hope increases your sense of control.

Locate Resources — Learn about and utilize local resources. Knowing help and support are available reduces anxiety.

## Key #4: Change the story of your pain

Caregivers often face painful situations that they cannot change. One obvious example is when a progressive disease is harming the person for whom you are caring. You can add comfort, but witnessing a loved one's pain is a heartbreaking task. You can't change that situation, and it hurts terribly. There are also challenging relationships, siblings who decline to offer support, and many of the situations we examined in Figure 5. You may have little influence over these events. But there is still hope when you can't change a painful situation.

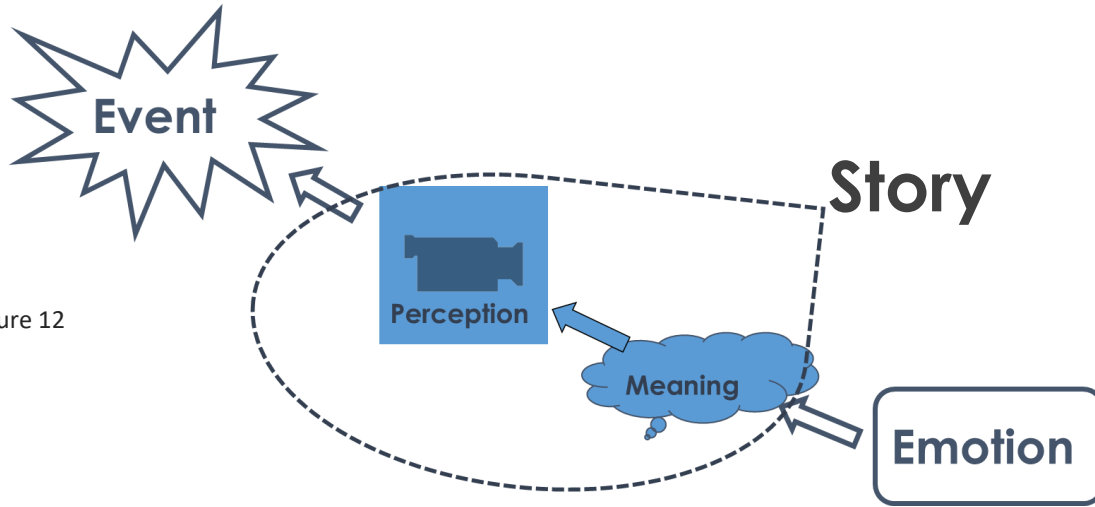
Figure 4, the exercise with which we began, illustrates our typical understanding of emotional response. It seems that our emotion is a *direct response* to some event. We say things like, "I am angry because she said that to me," or "I feel sad because I lost my job." The anger and sadness seem to be a direct response to a person's comment or a job loss. But if emotions were a direct response, then anyone who experienced the same event would respond with the same emotion.

Reality is more like Figure 12. We are responding only *indirectly* to the event, because that situation passes through a filter of our own making. That filter is what I am calling the **story** — your unique way of perceiving and interpreting the event, the meaning you give it. Recall that the triggers we examined with Key #2 were all about *perception* — *perceived* injustice, *perceived* danger, etc. Your story about the event, rather than the event itself, contains those triggers, those perceptions. Therefore, it is the story, with its embedded triggers, that evokes your emotion.

The good news is that if you can't change the situation, you may be able to change the story you tell yourself about it. And that new story (its alternative perception and meaning) will evoke a different emotional response.

The story you see and tell yourself about an event is powerfully shaped by your personal history and past relationships. Your history makes you notice and focus on some elements of the event, while it also blinds you to other elements. Your story may change if you notice something new in the situation, something that was previously hidden from view. But how do you begin to see what is hidden?

Figure 12



### How to Change Your Story

Changing your story isn't easy. It's a process you can't really force. It's something that happens to you, an epiphany, an "Aha!" moment. All you can do is create a climate, a lifestyle, that is open to that kind of change. When you practice the first three Keys, you prepare yourself for this change.

Key #1 Normalize — Remind yourself that painful feelings are normal in caregiving, so be kind to yourself when you feel them. Normalizing reduces your resistance to the feeling. (Resisting only makes the emotion cling to you and gets you stuck in your story.)



**Key #2 Analyze** — Step out of the pain by asking questions about the threat or the trigger of your pain. Begin to know yourself as the one who experiences the feeling. Analyzing loosens the grip the emotion has on you, and it loosens the grip of the painful story.

**Key #3 Practice to acquire resilience** — Find something in the list of practices in Key #3 that you can begin to do regularly. Start as small as you need to and grow from there. They will reduce stress, increase alertness, and make it easier to see what may be hidden beyond your history's blinders.

**Talk to a supportive listener** — Because the stress of caregiving induces a kind of tunnel vision, it is even more difficult for a long-term caregiver to imagine other ways of perceiving a situation. It helps immensely to share your perceptions and responses with a supportive friend, a pastor, or a counselor who may see your situation from a different angle. This supportive confidante may be human or divine.

### **Examples of Changed Story**

"I used to feel incredibly guilty for moving my husband to a memory care unit, but now I see that it was the disease that moved him there. I just did the legwork. I still feel guilty sometimes, but I can let go of it."

"I was so depressed when I was fired, but actually it opened the door to a job where I could spend more time with my family. And I would never have quit on my own. Now I consider it a blessing."

"I was constantly resentful of my sister for her denial that anything was wrong with mom, but now I see that she could not deal with the unpredictability of dementia. She desperately needs to have her ducks in a row. She can't bear to look at the chaos. I have more compassion for her now."

"I was a ball of anxiety, always looking for the next shoe to drop, wondering what would happen, knowing it would be worse than today. Then I realized that the haphazard downward trajectory of this disease offered me some random pleasant moments too — even some funny ones. I try to focus more on those, and I'm not so tense."

# Appendix

One model of emotions developed in 2006 for computer applications\* described **Angry** feelings as “negative and powerful,” **Sad** feelings as “negative and passive,” **Afraid** feelings as “negative and out of control,” and **Guilty** feelings as “thought-based.”

Anger increases blood pressure, makes your heart pump faster. People clench their jaws, tighten their fists, become flushed. Along with the emotion comes energy intended to move us into action. That is the “powerful” nature of anger. In fact, some people become addicted to anger because of this energy it brings with it. Some people prefer anger to sadness or guilt, because at least with anger they feel powerful.

If anger is *energizing*, then by contrast sadness is *enervating*. It depletes our energy, makes us withdraw from relationship and activity. It makes us “passive.” This is part of its positive purpose in healing from loss. If you break a bone, you will wear a cast or sling for a time to avoid normal activity, stress, and motion. This gives the bone a chance to mend itself. If your heart breaks, it also needs time away from your usual engagements, activities, and stresses, so it can have a chance to mend. Sadness is part of the physiological system that works like a cast for your broken heart.

Fear and anxiety often erupt amid chaos. Either we view the situation as “out of control” or we perceive that whoever is in control of the situation is not to be trusted, unpredictable. Think of a time when you were anxious or afraid and see whether this fits your experience.

Guilt is said to be based more in thought than the other emotions, because in order to feel guilty you must make a mental judgment. You have to decide that your behavior has violated your own moral code, your values.

*\*The emotion annotation and representation language (EARL) proposed by the Human-Machine Interaction Network on Emotion (HUMAINE) classifies 48 emotions. It is designed for representing emotional states in technological environments.*

## **Author**

Barbara Hemphill earned a B.S. in Mathematics from Texas Christian University and a master's degree in Practical Theology from Loyola Institute for Ministry in New Orleans. She completed four units of Clinical Pastoral Education with Memorial Hermann Health System and spiritual direction training through the Episcopal Diocese of Texas' FIND program. She has worked as a reservoir engineer and engineering programmer, and as Pastoral Care Coordinator at an Episcopal church. Barbara has published two books of poetry and prayers, one of which won an Independent Publishers Book Award. Since 2002 she has facilitated the Lake Houston Alzheimer's Caregiver Support Group. In 2014 Barbara and her friend Donna Composto of Mom's Care Plan established Kingwood Memory Café, a nonprofit that assists families living with early-stage dementia.

## **A Personal Note**

This booklet is a synopsis of a presentation I have given at the Kingwood Caregiver Conference and to church ministry groups. The ideas presented here come from my experience as a support group facilitator, hospital chaplain, spiritual director, church pastoral care coordinator, and as a caregiver for my mother and my mother-in-law, both of whom had dementia. These practices have helped me, and I hope they will benefit you.

The concepts from the original presentation are here, but with printed material, there is no opportunity to shed more light on anything that doesn't make sense to you. The requirement for brevity may reduce clarity and make it more challenging to apply.

So, if you read through this and have further questions, please contact me at [barbara@synapsesite.net](mailto:barbara@synapsesite.net).

*Barbara Hemphill*