“POP!” Creating a Space for “Pockets of Positivity” While Being a Caregiver
By Lorraine Gahles-Kildow, PhD

A caregiver’s story.

“I am a caregiver, my experience is unique and yet it is also universal. I vacillate between despair and anger. These persistent negative emotions are a relatively new pattern for me. I feel jealous, I feel resentful, I feel bitter, I feel frustrated, I feel numb, I feel detached, I feel like I want to escape, I feel paralyzed, I feel sad, I feel ambivalence, obligation, a sense of duty, and also a moral sense that this is the right thing to do. And, I feel love, but that emotion is becoming less frequent. Caregiving takes its toll on me. I didn’t realize that I was experiencing compassion fatigue until I became physically ill. My body screamed the message to me because my consciousness and my brain just wouldn’t let it in. When I went to the doctor, it was found that my protective antibody response in my immune system was low. I realized that I had to find a way to positively cope with my stress. During this time, I had a dream one night that I was on this cliff and I was on this beautiful mountaintop, and I could see the distance and it was gorgeous. I was in awe of nature in all its glory. But, then I looked down and once again realized I was on the edge of this cliff! All of a sudden I started to fall and I was hanging on to the edge and I couldn’t hang on much longer. Out of nowhere a friend appeared from above, with mountain climbing equipment. He threw me a rope and pulled me up. Upon awakening, I recalled the dream and thought, why this unlikely friend and what was this message? As I pondered the symbolism, I remembered that this person had said several weeks prior, “You have the privilege of being able to take care of your mother.” When he had first said that to me, I laughed. “Oh my gosh, a privilege?” That was so funny, it was ironic! “It’s a privilege?” It did not feel like a privilege at all! It felt like a very heavy burden. But as I interpreted this dream, I realized it is a privilege. Even with all these feelings of mixed emotions, of the stress and trauma and vicarious traumatization in watching my mother slowly decline, and sometimes not so slowly, even in the midst of all of that, I do have the privilege of helping her through this last stage of her life because I love her. And for some reason, after I interpreted that dream, I realized that, even though I had laughed at it, it was the key to me feeling better. I now had a different perspective of my situation. It was a privilege, it is a “sacred space” to help loved ones. Sometimes we forget that we are in this sacred spot, and we forget the true meaning of this “pocket of time” where we are sharing our love. I am reminded of a conference I attended years ago entitled spirituality and medicine. A palliative care nurse spoke about her years in helping people at the end of life. What resonated with me was that she said one of the most important things you can do is to sit and just be with that person and that family and bear witness to their suffering. That is the sacred space, an honorable space and it is at the heart of being a caregiver.”
This caregiver’s story reminds us that a shift in our “mindset” or perception of what is happening can have a dynamic effect on our stress levels, our physical health, our emotions and our sense of well-being. It is important for caregivers to strategically induce this shift in mindset so that it can buffer against many of the negative emotions that one experiences during this challenging time.

Psychological research has told us that caregivers can and do experience an overwhelming amount of stress when caring for their chronically ill. The term “compassion fatigue” has been used by Collins and Long (2003) to define a type of burnout that occurs with people who care for others who are dying, ill, or have a chronic mental or physical condition. It is “a feeling of deep sympathy and sorrow for another…with a strong desire to alleviate the pain and remove the cause.” One can develop a type of emotional exhaustion that produces physical and psychological distress, especially when you can’t alleviate the pain or remove the cause, as is the case with the chronically and terminally ill. Some of the indicators that caregivers can recognize are: frequent and persistent distressing emotions, psychological numbing or avoidance and escape behaviors, somatic complaints, physical illness, addiction or compulsive behaviors, hypervigilance, hyperarousal, feelings of isolation, depression, and even suicidal ideation. When we witness something distressing, or sad or traumatic, a natural part of our stress response system is to activate our Fight, Flight, or Freeze response. As in the above caregiver’s story, the person felt resentful, bitter, and frustrated (a form of the fight response), detached and wanting to escape (a form of the flight-escape response), and numb and paralyzed (a form of the freeze response.)

The research on stress has predominantly told us that persistent and continual stress is bad for our health. The work originally done by Hans Selye informed us that stress can induce physiological and hormonal changes in the body and that continued stress can lead to physical illness.

Researchers have used this concept to investigate the impact of stress on caregivers. Specifically, Vitaliano, et al. (2003) has reviewed research on the physical health of caregivers of people with dementia. They suggest that the chronic exposure (on average from 3-15 years) to the physical and psychosocial stressors of caregiving can produce allostatic load (wear and tear on the Hypothalamic-pituatary- adrenal (HPA) axis from repeated arousal and persistent secretion of cortisol and epinephrine) that then may influence illness, such as cardiovascular, metabolic or immunologic dysfunctions. In addition, caregiver distress may trigger risky health behaviors, such as “poor diet, sedentary behavior, and substance abuse.” They propose a model that suggests that illness is related to exposure (caregiving in this example), vulnerability (age, sex, race, disposition, family history, heredity), and resources (coping, social supports, etc.) Vulnerability and resources are variables that can moderate the effects of exposure according to their theory. These moderating variables can be sources of intervention for the caregivers. Lazarus and Folkman (1984) suggest that stress is a result of 2 components: viewing the situation as a “threat” and our “appraisal” of whether we have the resources to cope with it. Vitiliano, et al. (2003) found that widows had higher perceived efficacy in interpersonal activities and social support than widowers and thus showed more adaptation to stress in the caregiving situation. Widowers who had higher negative bereavement experiences also showed higher rates of disabilities, such as diseases of the circulatory system and even mortality. Billings, et al. (2000) as cited by Vitiliano, et al. (2003) has shown that social coping among caregivers was associated
with positive affect and lower levels of physical symptoms. In addition, the positive psychology literature suggests that finding “meaning” or “the silver lining” or “gratification” in your experience can enhance a subjective sense of well being. Being in a positive affective state activates the parasympathetic nervous system responsible for calming the flight, fight, or freeze stress response and putting reserves back into our body, thus, quieting the HPA axis promoting physiological regulation rather than dysregulation. In fact, work done by Barbara Fredrickson and others has shown an “undoing effect” of positive emotions on cardiovascular reactivity. Fredrickson proposes that positive emotions also serve to broaden our thinking (she calls this “pathways thinking”) and build our personal resources (psychological resources like resiliency and social resources like affiliation and bonding). One of my favorite studies by Fredrickson is called “Open Hearts Builds Lives.” In this experiment, she has one group of subjects induce positive emotions through nine weeks of lovingkindness meditation. The lovingkindness meditators end up not only inducing positive emotions while meditating but also find themselves showing more spontaneous positive emotions, more reported subjective well-being, less depressive symptoms, and fewer physical symptoms over the control group who did not use lovingkindness meditation. To me, these are such profound effects for something that is simple to do. Although Fredrickson was inducing a positive emotion through lovingkindness in this experiment, it is my opinion that she was also changing a “mindset.” She was activating the “tend and befriend” perceptual mindset.

According to Kelly McGonigal in the “Upside of Stress,” our stress response is not always bad. Stress is adaptive, it prepares us for something. Sometimes we feel the adrenaline rush and label it “stress” and “bad,” but it might be activating our “Challenge system” for action, for example, if your ill loved one is struggling to breathe, your adrenalin response helps you rise to the challenge. That’s good. Your stress response is working for you. You could conceivably call this “stress” and no one would argue with you about that. But, you could also perceive it as you rising to the challenge. McGonigal also makes the case that stress produces a tend- and-befriend response or a “higher than self” response. Distress can cause us to help and care and support those in need. In this case, oxytocin is released and love and social affiliation is felt. It makes sense then that we can consciously appraise the situation differently, we can intentionally change our mindset and we can strategically induce positive emotions while being a caregiver. In this way, we are increasing our psychological resources and building resiliency in the face of our adversities.

So, how can you find “pockets of positivity” “POP!” while being a caregiver? Here are 5 easy steps to take from a recently released program by this author:

1. **Create a space for positive emotions** - Research has shown that about 3:1 is the ratio of positive to negative emotions for a sense of well being- hope, joy, excitement, humor, laughter, contentment, interest, pleasure, curiosity, and forgiveness. Find them in your daily activities and interactions or plan to set up your environment to experience them. Cultivate optimism - optimists strategically induce positive emotions (find the good things about the situation, about the care recipient or about you. Savor gratitude or find 3 good things that happened each day.

2. **Be aware of your mindset** - As in the example above, this caretaker was focusing on the burden and stress of caregiving, not the “above-self” view or the “challenge” view.
Try to pay attention to your view of the situation, your loved one, and yourself.

3. **Be aware of the physical and psychological toll on you** - Are you getting sick more often lately? Do you have high blood pressure now? Make a plan to address this through positive coping strategies rather than avoidance coping or other maladaptive strategies. Don’t judge yourself for having negative emotions, they are a normal part of life and to be expected in this struggle.

4. **Imagine your best possible self** - in this situation or in the future and then try to experience it. Reflect on your strengths, your character, your values, and your moral compass and live through them purposefully and meaningfully.

5. **Meditate** - Mindfulness meditation has shown that one can decenter from ruminating on negative thoughts by focusing on the present moment and just observing in a nonjudgmental way, thus decreasing emotional reactivity and perceived stress and increasing well-being. Practice lovingkindness meditation for yourself and for your loved one.

    **POP!**
    
    *A lovingkindness Meditation for you*
    
    I am a caregiver and love is an elevated self.
    May I be filled with lovingkindness.
    May I be safe from inner and outer dangers.
    May I be well in body, mind, and spirit.
    May I be at ease and happy.

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