

Once again, I was feeling tense with a knot in my stomach. I was preparing to leave town to speak at a conference. I was doing my utmost to ensure my mother had everything she might need.

I purchased her favorite snacks, and extra incontinence supplies. I made the special wheat bran, applesauce and prune juice concoction we use to keep her bowels moving regularly. I alerted the assisted living staff and our private caregivers. Then I sat down on the little stool beside her chair, to tell Mom.

I explained where I was going and why. She gave me her “look” -one that says she is angry or frustrated, and answered, “Well, what do you want ME to do about it?”

What I want to hear is, “Thanks for letting me know.” Or maybe “Be careful and have a good time.” I long to hear, “You are speaking at a conference? I am so proud of you!”

But she can’t – or won’t. Sometimes I am unsure what behavior is driven by the dementia and what is her typical resentment, or intent to hurt.

You see, things have never been easy between my mother and me. Yes, we love each other. But Mom can be challenging. She can be negative and demanding and has always had a way of making you feel you were not quite good enough.

And then roles reversed and I had to become the one in charge. Intellectually, I get it. She sees me as the enforcer of her punishment, the warden of her prison. I am the mean one who urges her to take her meds and drink more fluids. I am the bully who tells her to eat two more bites at meals. I am the enemy.

I do my best to make her comfortable. I manage her money; find qualified caregivers to keep her company and assist her. I visit almost daily. I seek out the best doctors and each week I make the concoction that keeps her bowels moving regularly. Yet, I still feel guilty. And I feel hurt. I can’t completely avoid the stab of pain when she gives me ‘the look’ or says hateful things. I regret she sees me as the bad guy.

During many years of working with and advising caregivers, I heard this story over and over. I know I am not alone. Guilt seems to be ever present with caregivers. I am also not alone in my determination to be different, as I age. I don’t want my children to experience what I have experienced. I want to ease the burden for them. And other caregivers say the same thing.

Years ago, I stumbled upon a document called “The Caregiver Bill of Rights.” Created by Jo Horne, it lists the “rights” of caregivers. It’s fairly simple and logical. It lists things that we caregivers have a right to experience and expect, such as: the right to take care of oneself, the right to feel appreciated, etc.

As I began sharing this document with caregivers, many breathed a sigh of relief. A few got tears in their eyes. Some began to feel better about the tough decisions they had made. I watched some let go of guilt. These simple statements lightened their load a little.

As I walked the caregiver road myself, I am convinced we must begin to plan sooner for our “old age.” We must have those “critical conversations” with family members and significant people in our lives

sooner rather than later. I also believe we must be realistic about what we want and expect. We should acknowledge what may not be possible, versus our fondest hopes.

Recently, as I watched the live broadcast of the White House Conference on Aging, I heard many state emphatically they wanted to remain at home as they age. But I also have seen many situations where this is simply not possible, nor practical. And the guilt felt by the family members who must make tough decisions is compounded by that plea or promise made years before. Even the best planning may not foresee what the future may hold. And we should never underestimate the power of guilt, nor the power of words that might ease an emotional burden.

So, I have created a new document. Just like the *Caregiver Bill of Rights*, it's not legally binding. It may, however, serve as an "emotional hall pass," for my family when the times comes that I am no longer logical or rational or able to speak. I view it as an addition to my legally binding advanced directives.

And I am a Baby Boomer. We Boomers like to take charge, lead the pack, and change the status quo. We value individual choice and freedom. So in my efforts to take charge of things, though I may lose the ability to be in charge, here is my gift. It is for my husband who has endured my quirks, my passions and my own kind of crazy while I am fully, cognitively intact and for my children, the lights of my life, my greatest joy. It is my commitment, and rational promise to help them should they have to make challenging decisions about my care in the future.

Am I being naive? Is it silly to think this will be helpful? I don't think so. Yes, we should arrange those legally binding documents that clearly state our wishes. But just as we might leave letters for our children to read once we are gone, or we may designate sentimental heirlooms to our heirs, this is one more way to show love and understanding and to ease emotional pain for those we cherish.

True - it's just words. But words have power. And caregiving is a tough job. Anything I can do to ease the burden for those who may have to provide care for me, I am committed to doing. I love this quote from Dr. Stephen Hoag, who wrote the book *A Son's Handbook: Bringing Up Mom with Alzheimer's/Dementia*. *In an interview he said "No matter what the relationship was between the parent and child – whatever it was- this is going to be extremely challenging because it is not logical. There's no way to deal with it rationally or directly. You don't reason it out. What I've said to many people is we must always lead with love."*