

From <https://www.aarp.org/caregiving/life-balance/info-2017/tips-to-stay-positive-fd.html>

# Repeat After Me: I Am a Good Caregiver

## Four tips to counter feelings of shame and inadequacy

by Barry J. Jacobs, [AARP](#), July 6, 2017

Friends think Betty, 52, does a superb job caring for her aging mother, Faye. She sees or speaks on the phone with her mom daily. She drops off dinners at her retirement-community apartment. Though racked by arthritis, Faye seems to be thriving.

But Betty (a former client of mine) always winces when her friends praise her. She can't bear their compliments because they sound false to her, as if she somehow has fooled everyone. Where friends see competence and devotion, Betty sees her own inadequacy and ambivalence.

Even when Faye thanks her profusely for stopping by, Betty recoils, remembering the times when she didn't feel like visiting, forgot a promise she'd made or didn't do as much as she heard other daughters do. It's hard being a caregiver. But it is even harder for Betty because she is filled with shame.

Noted social work researcher and best-selling author Brené Brown (*The Gifts of Imperfection*) says shame is “the intensely painful feeling or experience of believing that we are flawed and therefore unworthy of love and belonging.”

If guilt is about feeling bad for what we've done (or haven't done), then shame is about feeling bad for who we are. It generally stems from early childhood, when we may have felt inadequately loved, leaving us feeling unlovable even as adults. We then judge ourselves harshly and discount our own accomplishments. Many earnest and diligent [caregivers suffer from shame](#), beating themselves up even as they are wearing themselves down.

Unfortunately, dispelling shame is no easy task. This is especially true when out-of-state relatives and the care receivers themselves offer subtle or withering criticisms, compounding the caregiver's negative self-regard.

Here are four ways caregivers can better appreciate their good deeds.

**Name the shame.** Many caregivers fault themselves for forgetting loved ones' [medical appointments](#) or flubbing minor tasks. The job doesn't require perfection. Try to step back from your caregiving routine to reflect on whether you take for granted all you get right and fixate on what you occasionally get wrong.

**Challenge your feelings.** Don't believe everything you think or feel. Others may have a more realistic perception of you. So when you receive a compliment, let the positive assessment soften your harsh view of yourself. One proviso: If family members have been hard on you about your caregiving performance, don't heed their judgments. Instead, [listen to other caregivers](#), who can truly relate to what you're going through and can more accurately value what you're doing.

**Guard against negative criticism.** Typically, most shame-prone people have specific triggers — or critics — that prompt them to castigate themselves. That well-meaning but judgmental older sister who offers you constructive criticism can stir awful self-recriminations. Anticipate such interactions and protect yourself from their caustic effects before they happen with positive affirmations like this: “My sister doesn't understand me or my caregiving responsibilities. I'm doing my best and getting the job done.”

**Separate present from the past.** Shame is the way the past haunts us, sending us old, negative messages about ourselves. Those messages are yesterday's news, and they don't reflect our current capabilities in meeting today's caregiving tasks. Judge yourself on what you accomplish now and every day. And remember to be as kind to yourself as you are to the person lucky enough to be receiving your care.

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From <https://mymotherscaregiver.com/blog.php?categoryID=44&category=Brene-Brown>

## SLAYING SHAME

by mymotherscaregiver

FRIDAY, DECEMBER 07, 2012

I wasn't even finished the first chapter before a light bulb had gone off in my brain. The words I was reading were so profound, yet so simple. I wondered how it hadn't occurred to me before. Suddenly, I found myself talking about *Daring Greatly*, by Brene Brown, in every conversation. I felt like a new apostle who had to share the good news – “We all live in shame, but we don't have to anymore!” The book changed me.

As I have mentioned many times before, Mom's dementia and delirium hit our family like a sand storm. We didn't even see it coming. It also came to head a few days before Christmas. Difficult, heart breaking decisions had to be made. Her safety became paramount and her rights and sometimes dignity came second. It was a horrible few months that still hurt remembering.

There was blame; some from within... and some from without. “How could you? Why did you allow that? What kind of daughter would...?”

By the time her nightmare ended and she'd begun to find peace, I felt like there were a thousand bees buzzing inside me, so I began to write this blog. Even as mom settled into the rhythm of long term care, I wrote about health care hurdles and the gaps in the system. I wrote about loss and love and grief. I felt compelled to share, with everyone and anyone I could, the things I had learned and the emotions that I carried. For surely if I felt this way, others must to.

Soon after I was speaking to every medical community and caregiver group that invited me, trying to make something good come out of something so terrifying – becoming a dementia-care “evangelist”, of sorts.

But it wasn't until I finished *Daring Greatly* that I had a name for the gnawing feeling I still carried around – even two years later.

Shame.

As caregivers we all face guilt for not doing enough. But this monster is stronger than guilt. False-guilt fades when faced with the facts, but shame is like arthritis – it aches in your bones every time the weather changes. Every time someone writes me or tells me what a great daughter and advocate I am, I shudder a little. If they only knew... they'd unsubscribe.

And so, it is time.

It is time to face this giant and slay him dead. Maybe you can help me. Maybe I can help you.

And so I declare:

- I am a good daughter, not a perfect daughter, but a good one who loves her mother very much and always will.
- I will not spend another micro second trying to convince others or justify the actions I took during mom's darkest days. I did the best I could with the information and resources I had and if no one on earth believed that, it wouldn't make it any less true.
- Other people's opinions of me, no matter how much I respect them, are not the basis for my self-worth. In layman's terms: "Who cares what anyone thinks!?"
- I will forgive and embrace grace, not just for others but myself. I will not resort to blame and bitterness when I am feeling vulnerable or falsely accused.
- I will stop rehearsing past hurts in my mind. It's time to stop sucking on this bitter candy and spit it out for good.
- My writing and speaking will never be a quest for redemption or penance. My motives will be pure: to share information, to help facilitate change, to love and support others emotionally and to be a light in a dark and lonely world.

So, good-bye Shame! Hit the road buddy, you ain't welcome here no more!

Here are links to some of Brown's talks and website – they might just change you too:

[https://mymotherscaregiver.wordpress.com/2012/12/07/slaying-shame/daringgreatly\\_final525/](https://mymotherscaregiver.wordpress.com/2012/12/07/slaying-shame/daringgreatly_final525/)

[http://www.ted.com/talks/brene\\_brown\\_on\\_vulnerability.html](http://www.ted.com/talks/brene_brown_on_vulnerability.html)

[http://www.ted.com/talks/brene\\_brown\\_listening\\_to\\_shame.html](http://www.ted.com/talks/brene_brown_listening_to_shame.html)

<http://www.ordinarycourage.com/>

from <https://thecaregiverspace.org/self-compassion-mindfulness/>

## **Self-compassion and mindfulness**

by Danielle, The Vibrant CareGiver | Mar 30, 2015 | Caregiver Stories

Over the past five years of caring full-time for my husband, I have discovered the necessity and obligation of self-compassion. It is only in the last two years, self-compassion has become my daily passion and practice. I take time to myself; to care, love, and have great patience for myself. The beginning of my journey to self-compassion was challenging, slow to progress, and now is vibrantly messy!

My first step was learning to take the same care, patience, and love I was giving to my husband, and apply it to myself, just as generously. I had to learn -I am not my thoughts, insecurities, or feelings of worthlessness. In fact, I was the only one hearing these thoughts, and more unfortunate- believing them.

Guilt, for us CareGivers, stems from feelings of not doing enough, being enough, trying to please everyone (and failing miserably). Our guilt is further fueled by not behaving in the “right” way, whether or not your perceptions are accurate. CareGivers often burden themselves with a long list of self-imposed “oughts,” “shoulds,” and “musts.” For example: “I must avoid putting Mom in a nursing home.” “I ought to visit every day.” “I shouldn’t lose my temper with my Loved One who has dementia.” Finally, self-imposed guilt, for many CareGivers happens by beating ourselves up over faults that are imagined, unavoidable — or simply being human.

So, how do we learn to cope? We become our own best advocate, friend, and self-CareGiver. Caregivers need to have self-empathy and self-compassion. I know, easier said than done. As a society we typically frown upon putting oneself first; however, how can you fill someone else’s cup when your own vessel is empty?

When guilt nags, ask yourself: What’s triggering the guilt? Could it be an unrealistic belief about your abilities? CareGivers intentions are good, but our time, resources, and skills are limited. We need to accept our limitations, the situation, and explore our feelings in these instances. We need to seek help in the form of family members, friends, neighbors, support groups, and/ or agencies.

We take care of ourselves, by establishing routines- simple, easy, and planned routines for us. A simple bedtime routine can mean better sleep, and a morning routine can set a positive tone to the entire day. Journaling is an instant release of pent up emotions, exercise or a quick walk can reinvigorate, and a daily devotion to a spiritual practice can ease stress. Simply stated, “Take care of you!”

My favorite author, Brene Brown, has this to say on the subject of self-compassion:

Self-compassion: Stop Beating Yourself Up and Leave Insecurity Behind.

Self-kindness: Being warm and understanding toward ourselves when we suffer, fail, or feel inadequate, rather than ignoring our pain or flagellating ourselves with self-criticism.

Common humanity: Common humanity recognizes that suffering and feelings of personal inadequacy are part of the shared human experience—something we all go through rather than something that happens to “me” alone.

Mindfulness: Taking a balanced approach to negative emotions so that feelings are neither suppressed nor exaggerated. We cannot ignore our pain and feel compassion for it at the same time. Mindfulness requires that we not “overidentify” with thoughts and feelings, so that we are caught up and swept away by negativity.” — Brené Brown, *Daring Greatly*

Always remember each day, hour, moment you can renew — try again!

From <https://blogs.sas.com/content/efs/2016/03/15/caregiver-guilt-the-gift-that-keeps-giving/>

# Caregiver Guilt: The Gift that Keeps Giving

By Kim Andreaus on SAS Life March 15, 2016 Work & Life at SAS

If you are a Caregiver, there is likely going to be a point at which you feel you aren't doing enough, you aren't doing it well, or a combination of the two.

So it's not really a question of "Do you feel Caregiver Guilt?" but "When do you feel Caregiver Guilt?"

Caregiving is accompanied by numerous emotions; including (but not limited to) impatience, anger, anxiety, resentment, feeling overwhelmed and drained. In addition, caregiving is often accompanied by dynamics such as sibling tension and a sense of feeling conflicted between your numerous roles; mother, co-worker, wife, sibling, and the tension between the needs of work, parenting and parental needs, and personal time. You tell a little white lie about needing to leave your mother to attend a meeting, then go home and lock yourself in the bathroom and run a bath – and feel guilt, or worse: Shame.

Some examples of caregiver guilt: (from "Life in the Moment")

- Regrets about being insensitive to the person's behavior before the diagnosis. You may also feel bad about not recognizing the signs earlier or putting off getting a professional diagnosis.
- Feelings of inadequacy about your skill or dedication as a caregiver.
- Guilt about dark thoughts that tend to blame the person for their condition.
- Feeling shame for a desire to take time for yourself (or feeling selfish for even considering your own needs)
- Guilt over missed opportunities to connect with the person
- Feeling that you have abandoned the person if you delegate their care to another person (or facility)
- Even moments of happiness can be difficult to savor, since you may feel guilt for experiencing joy at a time when your loved one seems to be beyond sharing that emotion.

Let's pause here and talk a little bit about the distinction between Shame and Guilt. Dr. Brene Brown has done incredibly powerful research on the topic of shame vs. guilt, and makes this very clear distinction between the two:

Guilt: I made a mistake

Shame: I am a mistake

In any of the examples above, I think some people might use guilt and shame interchangeably, but it is important to note the difference, as the psychological impact of shame is much more destructive. As Dr. Brown notes:

“Based on my research and the research of other shame researchers, I believe that there is a profound difference between shame and guilt. I believe that guilt is adaptive and helpful – it’s holding something we’ve done or failed to do up against our values and feeling psychological discomfort.

I define shame as the intensely painful feeling or experience of believing that we are flawed and therefore unworthy of love and belonging – something we’ve experienced, done, or failed to do makes us unworthy of connection.” She goes on to say that “shame, unlike guilt, is highly correlated with addiction, depression, eating disorders, violence, bullying and aggression.”

So, the first task is to check in with yourself to determine whether it is guilt you are feeling (which could be adaptive and lead to positive change) or shame (which is corrosive).

If it is guilt, try and recognize that (1) you will never be able to please everyone, and (2) guilt about having resentment, or anger towards your loved one, is common. Barry J. Jacobs, a psychologist and author of *The Emotional Survival Guide for Caregivers*, says "You love the person you're caring for, but you hate the caregiving. That's normal."

How to respond to caregiver guilt? First and most important, is to recognize what it is that you are feeling, so that you can then take steps to manage those feelings. At this point, self care is essential. Self care looks different for different people – so it is important to find strategies that will work for you and result in increased well being (which is the goal!)

Some suggestions:

- Keeping a journal to channel those negative emotions and get them “out” so that they are not bottled up inside you.
- Relaxation/meditation
- Exercise
- Respite can often be a lifesaver
- Talking with supportive friends
- Seeking support from other caregivers
- Forgive yourself
- Share your stories
- Try to focus on one day at a time (as thinking about the future can be overwhelming and non-productive)



From <http://www.portlandtherapycenter.com/blog/how-to-tell-the-difference-between-shame-guilt-humiliation-embarrassment>

## Shame, Guilt, Humiliation, and Embarrassment

Posted: July 12, 2014 by Kirk Shepard

Hello my name is Kirk and I am a Professional Therapist in Portland, OR and I'm happy to be able to share some really important information with you, as a guest here on Mental Help Desk. Today I am going to talk to you about the importance of self talk and how to tell the difference between shame, guilt, humiliation, and embarrassment. These come directly from the Daring Way curriculum based on the work of Dr. Brene Brown.

When I start talking about "shame" folks usually have a visceral reaction to the word and that's one of the reasons it is so pervasive in our lives.... because we shrink when we hear it, we try to dodge it, we pretend we don't have it or that it has nothing to do with us. The truth is that everybody has it and the less we talk about it, the more we have it. There's no way to overcome things in your life if you can't even utter the words. So spoiler alert: I'm going to be saying the word shame a lot in this video.

One of things that is so tricky about identifying shame is what I just mentioned about knowing the differences between shame, guilt, humiliation, and embarrassment. We often use these words interchangeably in our culture but there is a huge difference. Research over the last 12 years has demonstrated that people who have the highest level of shame resilience- and by shame resilience I don't mean that they were able to avoid shame all together or that they are a more perfect person because we know shame is impossible to avoid and perfection doesn't exist... what I do mean by shame resilience, is that they were able to identify shame self talk, know when it was happening, what triggered it, and what they needed to do to move through it with authenticity, courage, and self-compassion... these folks who showed the highest levels of shame resilience, had a few things in common and one of them is: they could tell the difference between these 4 self-conscious affects.

So first- let me kind of untangle shame and guilt. The most direct and easiest way to describe them is:

Shame="I am bad" Guilt = "I did something bad" Shame is a focus on self. Guilt is a focus on behavior. Say, you've been invited to attend a birthday party of a really good friend. You've been planning to go for weeks. Your friend is really excited to share the day with you. The day of the party you get caught up with some coworkers- you have a few too many drinks and you realize that you've completely missed your friends birthday party. If your immediate self talk is: "I'm such terrible awful friend. Oh, man, I'm such a loser." That's shame. If- (same scenario) If your self talk is : "ahh. I can't believe I did that. That was such a crappy thing to do, I made such a poor choice to have drinks before the party" That's guilt. Now, a lot of people want to reduce this to semantics. Shame, Guilt- I am bad, I did something bad.... Who cares how I say it in my head? Well, our self talk has a profound impact on us and on our relationships. Shame is highly correlated to aggression, addiction, depression, suicide, bullying, eating disorders, whereas guilt- the ability to separate who we are from our actions-without ripping away at our

worth- guilt is inversely correlated to these same outcomes. So as awkward as it may be- the more we can use guilt self talk- the less likely we will be associated with some of these outcomes. As you can see there's a tremendous difference.

So the next one is humiliation. There is only one ingredient that separates shame and humiliation and that is: deserving. With humiliation you get the same physical response as shame: palms get sweaty, heart races, you want to puff up or get really small... a great example that Brene Brown uses is: A teacher is handing back papers and one of the students doesn't have their name on the paper and the teacher calls the kid stupid: If that child's self-talk is "that is the meanest, most nasty teacher ever, I didn't deserve that" What that child is likely experiencing is humiliation. As a parent or caregiver- I'm going to hear about that when the kid gets home- because they're going to be angry and hurt and want to share it. If the child's self talk is immediately "ugh. She's right, I'm so stupid, why do keep forgetting to put my name on my paper, I'm so stupid," That's shame. And as a parent or caregiver I'm not going to hear about it- because the child believes they are stupid- and there is nothing to tell.

The last one embarrassment-is often funny and brief- but the most distinctive feature of embarrassment is that it doesn't leave you feeling utterly alone in the way shame does. So if I go out to lunch with some new co-workers that I'm trying to impress and in the middle of lunch I realize there's been a gigantic piece of kale stuck on my front tooth- I am able to laugh it off and move on- because I know that I'm not the only person in the world who has had food stuck on their teeth.

Shame is not funny and it leaves you feeling isolated and alone...

That's all I have for you today. I hope this helps you to start seeing patterns in your own self talk and supports you to start speaking some shame. If you need more support or are seeking more information on how to work through shame- you can contact me through my website- [rootstockcounseling.com](http://rootstockcounseling.com) - and I'll get you connected to the support you deserve.

From <https://www.psychologytoday.com/blog/the-clarity/201802/the-courage-show>

## **The Courage to Show Up: Highlights from a conversation between Brene Brown and DeRay Mckesson.**

Posted Feb 02, 2018

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Best-selling author Brene Brown and Civil Rights Activist DeRay Mckesson began a Twitter exchange that sparked the attention of millions. They sat down to continue the conversation in New York City in front of a sold out crowd at Riverside Church on February 1. Their conversation brought to light some of the psychological factors that create separation, fear and hate, as well as those that cultivate joy, empathy and gratitude.

Here are the highlights and key points, all backed by psychological research.

1. Joy is more vulnerable than pessimism. Cynicism and pessimism may lead to a false sense of security. Research shows that we have a negativity bias in that we look for and remember more negative than positive information. It's reasoned that because we need to be aware of possible threats and deal with them, they grab our attention. When our security feels threatened it can be very difficult to feel joy and positive emotions because our tendency is to keep on guard. Research on emotional resilience shows that people's capacity for joy is correlated with the degree to which they practice gratitude. Cynicism may be an easy choice, but we always have the option to cultivate joy, hope, love and courage. Pessimism is correlated with a wide array of physical and mental health problems too. Cultivating joy has many benefits. As the saying goes, "You can't give from an empty cup."

2. Dehumanization is dehumanization. The process by which we regard people as less than human because of the way they look or the attitudes that they hold is destructive. Dehumanizing others makes it easier to treat them with cruelty because we can't relate to their pain. Social psychologists have found that we have an in-group bias in which we see members of our own groups as more human and complex than people don't consider to be in our groups, called outgroup members. This tendency may be justified by believing that people who have very different political views are less human—so we can say cruel things about them on social media for instance. But in fact everyone is human and has basic rights to exist and hold their own beliefs. One way to prevent dehumanization is to engage with people who hold beliefs that you feel are threatening or "wrong" and then ask questions and listen more than you talk.

3. Guilt can be a good thing, but shame can lead to destructiveness. Brown makes the distinction between guilt and shame: Guilt is when you do something bad and shame is when you think you are bad. When people feel they are bad, they can feel justified to do destructive things to themselves and to others. Guilt is a form a cognitive dissonance that can create change if it stays in our awareness. It's difficult to feel the pain of guilt. We may feel guilt when we're made aware of a discrepancy between values and behavior. So we have to either change our values or our behavior—or what's more likely is to shift our focus so that the discrepancy is no longer painfully in our awareness. For instance, part of having privilege is the option to not say or do anything to change but to just keep the discrepancies out of awareness. Whereas when we lack privilege, the discrepancies are much harder to keep out of awareness because we are constantly

experiencing the effects of those discrepancies. So, privilege can be related to a lack of motivation for change.

4. We can empathize with anyone and everyone. You don't have to have had the same experience to empathize with someone. We all feel the same basic emotions. So instead of trying to cognitively understand what it's like for someone who's had an experience you haven't had or trying to put yourself in their shoes and thinking, "Well I probably wouldn't have reacted that way." Try recalling an experience from your own life in which you felt that same emotion like fear (or anger). By relating only on a cognitive level, we prevent ourselves from feeling vulnerable. We may never understand what it's like to be in that person's shoes—but as humans we know what it's like to feel fear, anger, vulnerability and joy. Everyone feels these emotions but may feel them under very different circumstances. So don't dismiss other people's experiences because you can't relate to the specific experience, instead relate to the emotion. It's also important to realize that some people feel fear occasionally, while others live in fear the majority of the time

5. Building a capacity to tolerate discomfort and uncertainty is key to change. Uncertainty is difficult to tolerate so we have a natural tendency to create stories that help us feel certain and feel safe. It's important to realize that these narratives aren't necessarily correct. Scarcity, fear, and vulnerability motivate us to find certainty, we may look to leaders whose messages make us feel certain and safe to satisfy our need. We can defend against our own pain by blaming and scapegoating others. Self-righteousness involves hostility, superiority and judgment—believing we're better than others and using that belief to avoid our own pain and to justify the pain we cause others. Change can happen if we develop the capacity to tolerate discomfort and uncertainty. Allowing ourselves to feel our own pain and not know everything, keeping open to possibilities that we haven't thought of yet, and being willing to risk having uncomfortable conversations are keys to creating change.

Takeaway Tweet: "Cultivate the capacity to listen with the same passion as you want to be heard."

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From <https://www.psychologytoday.com/blog/emotional-nourishment/201706/the-good-enough-daughter-is-it-okay>

# The Good-Enough Daughter: Is it Okay?

## How much sacrifice of self is enough when caring for a parent?

Posted Jun 15, 2017

Recently, researchers Bott, Schekter and Milstein wrote in JAMA Neurology that the best long-term care insurance for an elderly parent was a conscientious daughter. Bott et al., calculated that even caretaking for a parent without dementia takes about 66 hours a month, and for those with dementia, 171 hours. The findings that such caretaking demands fall upon women who may still be in the work-force, and possibly still parenting their own children, makes them jugglers of time and energy.

How does this all work out for the daughters? Our anecdotal observation of ourselves, our female friends, and our colleagues is this: it's not so good.

In his 1960 paper, published in the International Journal of Psychoanalysis, British pediatrician Donald Winnicott coined the term "the good enough mother" to delineate the psychological processes of empathy and mothering. As the infant's dependence on the mother moves from absolute, to relative, toward independence, the mother's caregiving moves from complete (perfect) sacrifice of self to the infant to becoming good enough (imperfect, incomplete). Permission to be a "good enough mother" comes from the awareness that the infant's growth comes from the movement toward independence. Yet, even in this theory there was ample room for chunks of guilt to be placed on the mother for misjudging and missing the infant's needs.

Guilt is what brings us to the "good enough daughter" (our derivative from Winnicott). How much sacrifice of self is enough when caring for a parent? Is it okay to be a "good enough daughter" by sacrificing keen awareness and ceaseless response to the elder parent's needs? How imperfect, and perhaps even inconsistent, can the caregiving be?

Complicating all of this are not just societal expectations, but if women are to be frank about this, our own expectations. It doesn't matter that our roles have broadened from mothering as the primary occupation, to occupying almost half of the U.S. workforce (wherein we hold positions of authority across a variety of fields).

"Good enough" may not be good enough.

Receiving A's at work does not cut it. Being a "good enough daughter" (if we are to be honest) may result in giving ourselves F's as nurturers. We risk failing as mothers to our mothers and fathers. Bott et al., found that daughters are 28 percent more likely to care for a parent than sons. Yet, there is a toll on daughters assuming a disproportionate amount of the care of their parents (and in-laws, as it turns out). The psychological effects are that of depression (some studies suggesting between 40 percent to a high of 70 percent of caregivers have symptoms approaching clinical depression), physical fatigue, sleep problems, and health problems.

Much of what daughters do for their mothers and fathers does come from love and empathy. But unlike the developmental process with infants, where the movement is toward independence, with our elderly parents the movement is toward dependence—physical, psychological, or many times, both.

The existential reality is rough. This type of caregiving is fraught with tensions, expectations, fears of parents' death, fears of our own death, and anxiety about not spending "quality time" with the elderly parent when it is still possible. In addition, there are feelings of resentment:

Spending all our quality time in non-quality ways.

Conflicts regarding the parent doing things that are maddening (e.g., not using a walker and falling).

Parent not trying to make our caretaking efforts or their own lives easier (e.g., forgetting to turn on the cell phone or refusing to learn how to use one).

It has long been known that the desire to be perfect takes a physical and psychological toll. Moreover, perfection is an abstract construct, subject to interpretation. In assuming a caretaking role for a family member, we must remember and ACCEPT that everyone has limitations (us as well as the recipient of our care). By keeping this thought foremost in our mind, the challenges of caretaking become less distressing. Doing the best you can, in concert with accepting the reality of the situational circumstances, is more than "good enough."

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From <https://www.psychologytoday.com/blog/understanding-grief/201705/guilt-and-grief-placing-loved-one-in-nursing-facility>

## **Guilt and Grief: Placing a Loved One in a Nursing Facility: Making hard decisions**

Posted May 02, 2017

One of the most difficult things I have ever had to do was to tell my mother that we were moving her to a nursing home. For my entire life, my mother had made it very clear to me that she never wanted to “end up” in a nursing home. I promised her that I would not let that happen and that she could stay with us until she died. In my mother’s 95th year, she fell, was hospitalized and declined rapidly. We sat vigil on several occasions when the doctors told us her death was imminent. When nothing more could be done, we brought her home to die. After several months, things progressively got worse and the nurses felt that her physical needs could best be addressed by transferring her to a nursing home. I immediately broke into tears and the guilt set in. I knew it was the right thing to do but how could I do that to my mother? It took me days to get up enough courage to tell her. At that point, my mother was in such a state of decline that I am really not sure how much she was aware of what was going on around her; but that did not diminish my guilt.

My story is not unusual, nor is the guilt that I felt. Unfortunately, guilt is a part of caregiving, particularly when you have to make a decision that you know is against the wishes of your loved one. Once in a nursing home, our pain is often escalated by our loved ones begging and pleading to be taken home. Each visit can become a nightmare of pain and suffering for you both.

Taking care of someone who is dying can be a Herculean task. Being a caregiver to an elderly parent, working full time, and raising a family are almost impossible tasks to juggle. Even if you do not work outside the home, it is still a daunting challenge to meet all the demands placed on you. Hiring caregivers to help ease the situation can also be fraught with its own set of problems that can be more stressful than doing it yourself. Additionally, there is also the expense involved that many cannot afford.

Recognizing the enormity of the tasks in front of us, all we can do is to try our best. We cannot possibly do it all, even though we may try. We feel over-responsible, out of control, and helpless at the same time. The result is experiencing caregiver burnout and resentment. Even if we could do it all, we would still find something to feel guilty about. It just goes with the territory. We all make promises with the best of intentions, but events and situations change and we cannot keep our word. We feel we have failed. We berate and blame ourselves for being human and for all those things we “should have” or “could have” done.

For the majority of us, the guilt we feel is unjustified. We have to remember that even though we feel guilty does not mean that we are. We are faced with decisions that we do not like or want to make but we have to do something that is in the best interest of all involved. In addition to guilt, there are myriad other emotions we live with at this time: angst, worry, sadness, anger, frustration, and resentment to name a few. We cry a lot and become short tempered. We

experience all these feelings even before our loved one has died. What are we to do? Below are some suggestions you might find helpful:

- Acknowledge that you feel guilty and accept that feeling guilt is a normal part of the dying process for caregivers.
- Recognize that you are only human and not some superhero who can do it all.
- Be careful what you promise your loved one.
- Be nicer to yourself. Meet some of your own needs for a change. Take the time to nourish and replenish yourself.
- Write down your thoughts and feelings.
- Talk to friends, family, or other caregivers.
- Talk to your loved one as if they are sitting across from you in a room. Tell them about your struggle with guilt and imagine what they would say. Most of our parents/spouses would not want us to be in so much pain and distress.
- If problems continue, seek out a mental health professional. Carrying guilt around can have negative consequences for your physical and emotional health.
- Consider this: Often it is easier to blame ourselves rather than be angry with others or the situation. It somehow makes us feel more in control. Maybe there is anger underlying your guilt?
- Forgive yourself. You are doing the best you can.



From <https://www.griefhealingblog.com/2016/10/in-grief-after-caregiving-ends-who-am-i.html>

## **In Grief: After Caregiving Ends, Who Am I?**

Monday, October 17, 2016 [Reviewed and Updated January 26, 2018]

Alongside the hole left by losing a loved one, a caregiver may be surprised to feel a different kind of loss: a foundering sense of purpose. It makes sense -- caregiving can be so consuming and can require such hard-won expertise that it can be difficult to regain a footing in "normal life" afterward. ~ Paula Spencer Scott

*A reader writes: My mother died 2 weeks ago. I had been her caregiver for 21 years. I don't know what to do or how to live. Everything I did was based on what was best for Mom. In the last couple of years, as Mom began to weaken, I became so depressed. I would care for Mom but neglected housework and yard work. I was always too tired. Now, I can do whatever I want, whenever I want...but I don't know where to begin . . . all of this stuff just makes me so tired. I just want to sleep or watch TV. Is this normal grieving? How do I shake myself out of this non-productive funk?*

My response: My dear, I can assure you that what you are feeling is normal. You're reacting to the fact that you've lost not only your dear mother, but your job as well. Caring for your mother all those years defined who you are, and now that part of your identity is gone. That is a significant loss that generates grief piled on top of grief, and it can cause you to question your very purpose in life. Who are you now, and where can you go from here?

I've gathered some resources that I hope you will find helpful as you find your way through this challenging time, and I hope you will take advantage of them:

**After Caregiving Ends, by Judy Tatelbaum, MSW** - The first step after any kind of loss is always to allow and accept our feelings. We must acknowledge this shift in our lives and the feelings it may provoke. It is possible that we'll feel relief that we don't have to work so hard any longer, and then feel a sense of guilt for feeling such relief. We may be angry with ourselves or someone else for letting us down. All of these are natural reactions. It is important to express our sadness, anger, loneliness, regret, and whatever else we may feel. Read on here. (<https://hospicefoundation.org/hfa/media/Files/after.pdf>)

**When Caregiving Ends, by Donna Schempp, LCSW** - Caregiving can last for many years. Caregivers set their own lives aside to care for someone else. When that person dies, caregivers have to figure out what to do with their lives now. There is no preparation for this transition. Generally you are so busy caregiving, and life changed so long ago, that there has not been time nor energy or even the psychological will to think about what comes next. Here are some tips that might help you during this time . . . Read on here. (<https://www.caregiver.org/when-caregiving-ends>)

**Feeling Relief (and Guilt) at Caregiving's End, by Barry J. Jacobs** - It is difficult to resolve the conflicting emotions at caregiving's end. But here are some ideas for alleviating the guilt they often cause . . . Read on here. (<http://www.aarp.org/home-family/caregiving/info-2015/relief-and-guilt-when-caregiving-ends.html>)

**Rebuilding Your Life After the Death of Your Care Receiver, by Carol Bradley Bursack -**

Many of us start our caregiving career by assisting an elder in his or her home, or we have a spouse who declines and we become the default caregiver in our own home. This care expands to a point where we need some type of respite, often in the form of in-home care agency help. Eventually, the move to assisted living or even a nursing home may become necessary for everyone's health and wellbeing. Whatever happens, we remain caregivers. Many of us continue to see our care receiver daily. Most of us continue to be involved as advocates and support throughout the time of need. When our loving attention and care is no longer needed, we can, indeed, feel lost. Read on here. (<https://www.agingcare.com/Articles/caregiving-ending-after-death-148071.htm>)

**Beginning Again After Caregiving Ends, a 6-Week Course by Denise M. Brown** – One-hour webinars you listen to at your convenience each week for six weeks. Need more time? Take as much time as you need; the webinars are archived and available when you're ready. You also can refer to the webinars as often and as much as you need. Cost: \$20. Read more here. (<http://www.caregiving.com/online-courses-for-family-caregivers-and-former-family-caregivers/beginning-again-after-caregiving-ends-a-6-week-course/>)

**After Caregiving Ends – From Caregiving.com**, a number of articles written by caregivers themselves, sharing how they coped in the aftermath. (<http://www.caregiving.com/articles/blogged/after-caregiving-ends/>)

**I've Lost My Sense of Purpose: Caregiver Confessions, YouTube** - In this brief "Caregiver Confession" video below, Leeza Gibbons acknowledges the same sense of loss that you are experiencing now, and offers some practical advice for regaining purpose after caregiving: (see [https://youtu.be/nKs\\_SlOuOw0](https://youtu.be/nKs_SlOuOw0))

As Leeza observes, there are many other caregivers "out there" who are facing some of the very same challenges you have learned to overcome, and they certainly could profit from whatever advice you'd be willing to share, once you feel ready, able and willing to do so.

I hope you will consider how you might re-connect with others. You might think of hobbies or other interests you once enjoyed that you've had to postpone for so long. When you have the energy, check out some of the resources in your community that are available to you now that you have the time to investigate them (e.g., your public library; book clubs; adult learning classes; exercise, workout and fitness centers).

At the very least, I hope you will recognize and give yourself the credit you deserve, not only for the priceless gifts you gave to your mother through caring for her, but also how much you have learned in your role as a caregiver. You may not realize it now, but as a caregiver for more than two decades, you've gained the sort of expertise and wisdom that comes only from practical experience, and that is a valuable commodity. At some point ~ and only if and when you are ready ~ you might consider offering your skills, either as a volunteer (see, for example, Healing Grief through the Gift of Volunteering) or by pursuing further education and training for a professional career in nursing, social work, geriatric care or elder companionship.

From <https://www.griefhealingblog.com/2012/12/grief-and-burden-of-guilt.html>

## Grief and the Burden of Guilt

Sunday, December 30, 2012 [Reviewed and updated January 14, 2018.]

*Guilt is perhaps the most painful companion of death. ~ Coco Chanel*

Guilt is a normal response to the perception that we've somehow failed in our duties and obligations or that we've done something wrong. It generates a jumbled mixture of feelings including doubt, shame, inadequacy, insecurity, failure, unworthiness, self judgment and blame, anxiety and fear of punishment.

When your loved one's terminal illness was finally diagnosed, as a caregiver you may feel guilty that you hadn't noticed symptoms sooner, waited too long to seek treatment or didn't do enough to comfort your beloved. If death came suddenly or unexpectedly, you may feel guilty for not being present when it happened. If it came after a long, lingering illness, you may feel guilty for feeling relieved that your loved one's suffering is over and you're now free from the burden of worry and care. You may feel guilty that you are the one who survived, or uncomfortable that you received an insurance settlement or inheritance following the death of your loved one. If you're a religious person, you may feel guilty that you feel so angry at God.

Unfortunately, guilt is a natural and common component of grief. When someone you love dies, it's only human to search for an explanation, to look at what you did or did not do, to dwell on the what if's and if only's. You agonize and tell yourself, "If only I'd done something differently, this never would've happened." Sometimes, though, there simply isn't anything you could have done differently. When your loved one's illness or death occurred, chances are that whatever happened beforehand was not intentional on your part. In the wise words of internationally known author and publisher Louise Hay, we do the best we can with our understanding at the time, and when we know better, we do better. Given the stress you were under at the time and how exhausted you may have been, you were doing the best you could. You were basing whatever you did on what you knew, given the information available to you then.

Harsh as it may seem, consider that even if you had done things differently, your loved one still could have died in some other way at some other time! Sometimes we act as if we can control the random hazards of existence, even when we know that death is a fact of life.

Guilt is driven by our own personal beliefs and expectations, and dealing with it requires that we examine what we think we did wrong, face it and evaluate it as objectively as possible. For example, what did you expect of yourself that you did not live up to? Were your expectations unrealistic? If they were, then you need to let go of them. Since you did all that you were capable of doing at the time, there simply is no basis for your guilt, and you need to let go of that as well.

Nevertheless, if after careful examination of the facts, you find that your expectations of yourself are legitimate and you still did not live up to them, it's important to face and take responsibility for what you believe you could have done differently. Healthy guilt allows us to own up to and learn from our mistakes. It gives us a chance to make amends, to do things differently next time, to come to a better understanding of ourselves, to forgive ourselves and move on.

### Tips for Coping with Guilt

- · Identify what it is that you feel guilty about. Resist the urge to keep such thoughts and feelings to yourself like so many deep, dark secrets. Bring them out into the open where they can be examined. Share them with a trusted friend or counselor, who can view your thoughts and feelings more objectively, and challenge what may be irrational or illogical.
- · Listen to the messages you give yourself (the should haves, could haves and if only's), and realize the past is something you can do absolutely nothing about.
- · When guilty thoughts come to mind, disrupt them by telling yourself to stop thinking such thoughts. Say "STOP!" firmly, and out loud if you need to.
- · Live the next day or next week of your life as if you were guilt-free, knowing you can return to your guilt feelings any time you wish. Pick a start time, and stop yourself whenever you make any guilt-related statements.
- · Write down your guilt-related statements, set a date, and pledge that from that day forward, you won't say them to yourself anymore. Post them and read them every day.
- · If you are troubled by feeling relieved that your loved one's suffering has ended, know that a heavy burden has been lifted from your shoulders; you have been released from an emotionally exhausting and physically draining experience, and to feel relieved is certainly understandable.
- · If you believe in God or a higher power, consider what He or She has to say about forgiveness.
- · Participate in a support group — it's a powerful way to obtain forgiveness and absolution from others.
  - Be your own best friend. What would you have said to your best friend if this had happened to that person? Can you say the same to yourself?
- · Remember the good things you did in your relationship with your loved one and all the loving care you gave. Focus on the positive aspects: what you learned from each other, what you did together that brought you joy, laughter and excitement. Write those things down, hold onto them and read them whenever you need to.

- · Ask what you expected of yourself that you didn't live up to. How is it that you didn't? What were the circumstances at the time? What have you learned from this that you'll do differently next time?
- · What can you do to make amends? Find a way to genuinely apologize to your loved one's spirit and ask for forgiveness.
- · Have a visit with your loved one. Say aloud or in your mind whatever you didn't get to say while your loved one was still living. Be as honest as you can be.
- · Have your loved one write a letter to you. What would this person say to you about the guilt and sadness you've been carrying around?
- · Ask what it would take for you to forgive yourself. Can you begin doing it? Say out loud to yourself, "I forgive you." Say it several times a day.
- · Remember that no one else can absolve your feelings of guilt—only you can do so, through the process of intentionally forgiving yourself.
- · When you've consciously learned all you can learn from this situation, and when you've made any amends you consider necessary, then it's time to let go of your guilt, to forgive yourself, and to move on.
- · Channel the energy of your guilt into a worthwhile project. Do good deeds in your loved one's honor.

# Caregiver's Bill of Rights

Developed by an Anonymous Caregiver Support Group

## **I have the right:**

### **To take care of myself**

I recognize that I must be healthy, physically and mentally, if I am to continue to provide care for another.

### **To seek help from others**

Even if the person I am caring for objects, I recognize that there are limits in my own strength and endurance.

### **To get angry and/or depressed**

I may need to express difficult feelings and have the right to seek appropriate avenues for their expression or assistance in dealing with these feelings.

### **To reject any attempt to manipulate me through guilt, anger, or depression**

As objectively as possible, I must make decisions regarding the care I provide, resisting manipulation expressed by or perceived from the person for whom I care, other members of the family, relatives, or friends.

### **To take pride in what I am accomplishing**

It is alright to applaud my courage, patience, and creativity it sometimes takes to meet the person's needs.

### **To protect my individuality**

I have the right to make a life for myself and engage in some activities that will sustain me in the time when the person I care for no longer needs my help.

### **To expect and demand resources**

It is important that I obtain the physical and/or mental aid and support for myself and/or the person for whom I care.