Caregiver Self-assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for their relative’s needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

1. Had trouble keeping my mind on what I was doing. □ Yes □ No
2. Felt that I couldn’t leave my relative alone. □ Yes □ No
3. Had difficulty making decisions. □ Yes □ No
4. Felt completely overwhelmed. □ Yes □ No
5. Felt useful and needed. □ Yes □ No
6. Felt lonely. □ Yes □ No
7. Been upset that my relative has changed so much from his/her former self. □ Yes □ No
8. Felt a loss of privacy and/or personal time. □ Yes □ No
9. Been edgy or irritable. □ Yes □ No
10. Had sleep disturbed because of caring for my relative. □ Yes □ No
11. Had a crying spell(s). □ Yes □ No
12. Felt strained between work and family responsibilities. □ Yes □ No
13. Had back pain. □ Yes □ No
14. Felt ill (headaches, stomach problems or common cold). □ Yes □ No
15. Been satisfied with the support my family has given me. □ Yes □ No
16. Found my relative’s living situation to be inconvenient or a barrier to care. □ Yes □ No
17. On a scale of 1 to 10, with 1 being “not stressful” to 10 being “extremely stressful,” please rate your current level of stress. __________
18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill,” please rate your current health compared to what it was this time last year. __________

Self-evaluation

To determine the score:

1. Reverse score questions 5 and 15. (For example, a “No” response should be counted as “Yes” and a “Yes” response should be counted as “No.”)

   2. Total the number of “yes” responses.
To interpret the score

Chances are that you are experiencing a high degree of distress:
- If you answered “Yes” to either or both questions 4 and 11; or
- If your total “Yes” score = 10 or more; or
- If your score on question 17 is 6 or higher; or
- If your score on question 18 is 6 or higher

Next steps
- Consider seeing a doctor for a check-up for yourself
- Consider having some relief from caregiving (Discuss with the doctor or a social worker the resources available in your community.)
- Consider joining a support group

Valuable resources for caregivers

**Eldercare Locator**
(a national directory of community services)
(800) 677-1116
www.eldercare.gov

**Family Caregiver Alliance**
(415) 434-3388
www.caregiver.org

**Medicare Hotline**
(800) 633-4227
www.medicare.gov

**National Alliance for Caregiving**
(301) 718-8444
www.caregiving.org

**National Family Caregivers Association**
(800) 896-3650
www.nfca-cares.org

**National Information Center for Children and Youth with Disabilities**
(800) 695-0285
www.nichcy.org

Local resources and contacts:
Caregiver Guilt
By Dorothy Womack

The role of a caregiver at home is usually accompanied by varying degrees of guilt. This happens regardless of our effectiveness, as it seems to be virtually impossible to care for our loved ones and simultaneously face the realities that we will inevitably lose them. Most of us eventually confront not only the loss of our loved ones, but the guilt that we could have done more, should have known better, would have done differently in retrospect. This increases not only our guilt, but our grief as well. We long to spare our loved ones from the ongoing progression of disease and death – but we cannot save or rescue them. As caregivers, I sometimes think we have placed on ourselves an unattainable goal. Deep inside we begin to believe that we are responsible for the life or death of our loved one. And we become helpless in the face of the inevitable; life in the body ceases to function and life in the spirit begins. Our loved ones depart houses no longer adequate to hold them and move onto a new dimension, while we remain behind, often shattered by our grief and shackled by our guilt. Our grief is only compounded when we are weighed down with guilt. The energy that we spend trying to desperately avoid the ultimate end is almost Herculean in nature. What we often do not realize is that at the end of human life exists a new beginning, not just for our loved ones but for us as well. And for many caregivers, the grief process can take much longer to work through. The guilt we carry slows the normal grief process as it drains the energy needed to work through it.

The holidays can be particularly difficult as we begin to dwell more at this time of year on our loss. Holidays are a time for family, and when a loved one has died, it can make surviving this season almost an impossible task. For many, our first reaction is to just not celebrate the holiday in effort to avoid the pain of our loss. Perhaps it would be better to look at this time of year as a way in which to celebrate the life our loved one lived, and to recall the comfort and joy these family traditions brought us in the past. This can provide one the chance to create new traditions as well, and in doing so help to move forward in the grieving process. Whatever decision is made regarding the holidays, try to make it from your heart. Allow yourself to feel. By suppressing our feelings, we only prolong the pain. And ultimately prolong the grief. Follow your heart and do not let guilt for what should have been destroy your peace of mind.

Guilt is destructive. It impedes our progress and inhibits our own destinies in this life. We spend our time berating ourselves for where we perceive failure instead of focusing on all the good we achieved, the quality of life we brought to our loved ones and the character development that ensued as a result. The best knowledge we can possess is that our efforts made a difference in the last days of our loved ones. There is no easy remedy for guilt. No magic formula we can use to erase it from our being. At best, it is an ongoing process, one that we must practice every day so that we can successfully eradicate guilt from our lives. We have to look in the mirror and confidently tell ourselves that we have done the best we were able to do. Given the tools we had to work with, we used our best judgement, and made caregiving decisions that we truly felt were in the best interest of all concerned.

It takes discipline to focus on the attainment of a higher level of living for all of us as the mortal bonds are broken. However, our loved ones live on in our hearts forever and those eternal bonds remain. The memories can be used to comfort us that much sooner if only we can cast off the guilt that simply clouds our vision and torments our minds. Peace then comes as we realize and acknowledge that there was purpose to all we shared. The lessons learned change us and equip us to better empathize with those who follow after along our paths of experience. Release the guilt you carry and listen with your heart. You will truly find your loved ones not only dwell in peace, but wish the same for you as well.
Eight Tips to Managing Caregiver Guilt
By Dr. Vicki

Guilt is a common feeling in the landscape of caregiving. Guilt can propel you to be the best you can be...or it can immobilize you.

For caregivers, painful feelings — such as guilt, sadness and anger — are like any other pain. It’s your body’s way of saying, “Pay attention.” Just as the pain of a burned finger pulls your hand from the stove, so, too, guilt guides your actions and optimizes your health.

You have a picture of the “Ideal You” with values you hold and how you relate to yourself and others. Guilt often arises when there’s a mismatch between your day-to-day choices and the choices the “Ideal You” would have made. The “Ideal You” may be a parent who attends all of the kids’ soccer games. Miss a game to take your dad to the doctor, and you think you’re falling short.

You may have needs out of line with this “Ideal You.” You may believe that your own needs are insignificant, compared to the needs of your sick loved one. You then feel guilty when you even recognize your needs, much less act upon them. A mother may ask herself, “How can I go out for a walk with my kids when my mother is at home in pain?” (A hint for this mother: she can give more to her mother with an open heart when she takes good care of herself.)

You may have feelings misaligned with the “Ideal You.” Feeling angry about the injustice of your loved one’s illness? You might even feel angry at your loved one for getting sick! Recognizing those feelings can produce a healthy dose of guilt. Yes, you may even feel guilty about feeling guilty.

“Why did my loved one get sick?” you may ask. Perhaps, if the “Ideal You” acted more often, your loved one would be healthy. What if you served more healthful meals? What if you called 911, instead of believing your husband when he said his chest pain was just “a little heartburn”?

If you’re the kind of person prone to guilt, learn to manage guilt so that guilt serves you rather than imprisons you. Here are eight tips for managing your caregiver guilt:

Recognize the feeling of guilt: Unrecognized guilt eats at your soul. Name it; look at the monster under the bed.

Identify other feelings: Often, there are feelings under the feeling of guilt. Name those, too. For example, say to yourself: “I hate to admit this to myself, but I’m resentful that Dad’s illness changed all of our lives.” Once you put it into words, you will have a new perspective. You will also be reminding yourself of how fortunate you are to have what it takes to take care of loved one.”

Be compassionate with yourself: Cloudy moods, like cloudy days, come and go. There’s no one way a caregiver should feel. When you give yourself permission to have any feeling, and recognize that your feelings don’t control your actions, your guilt will subside.

Look for the cause of the guilt: What is the mismatch between this “Ideal You” and the real you? Do you have an unmet need? Do you need to change your actions so that they align with your values?

Take action: Meet your needs. Needs are not bad or good; they just are. If you need some time
alone, find someone to be with your loved one.

*Change your behavior to fit your values.* For example, Clara felt guilty because her friend was in the hospital and she didn’t send a card. Her guilt propelled her to buy some beautiful blank cards to make it easier for her to drop a note the next time.

*Ask for help:* Call a friend and say, “I’m going through a hard time. Do you have a few minutes just to listen?” Have a family meeting and say, “Our lives have been a lot different since grandma got sick. I’m spending more time with her. Let’s figure out together how we’ll get everything done.”

*Revisit and reinvent the “Ideal You”:* You made the best choices based on your resources and knowledge at the time. As you look to the future, you can create a refined vision of the “Ideal You.” What legacy do you want to leave? What values do you hold dear? Then, when you wake up in the morning and put on your clothes, imagine dressing the “Ideal You.” Let this reinvented “Ideal You” make those moment-to-moment choices that create your legacy.

*Understand that you will be a more effective caregiver when you care for the caregiver first.* Loved ones neither want nor expect selfless servants. As a caregiver, when you care for yourself, you increase and improve your own caring. Yes, guilt is part of caregiving, but this guilt can help you become the caregiver you and your loved one want you to be.

Dr. Vicki is a board-certified surgeon and Clinical Instructor at the University of Washington School of Medicine who left the operating room to help caregivers and patients take the most direct path from illness to optimal health. You can email her at DrVicki@DrVicki.org.
Stuck in Caregiver Guilt?

January 30, 2008 by caroldodell

2 Votes

Caregiver guilt is debilitating. You know that the word, “guilt” isn’t a healthy word, but many caregivers feel overwhelmed with a sense of I should, I wish I had, why can’t I just...

I certainly experienced my fair share of caregiver guilt.

The irony is the more you do, the guiltier you feel. Trust me, the family members who have disconnected from their loved ones who need them feel far less guilt than you do. Why? Perhaps it is as simple as a disconnect. They just don’t “feel” it. It’s a safety valve. But those who get in the thick of the battle, who give time, money, energy, and day-to-day care are the ones feeling the most guilt. Crazy, huh?

Certain family dynamics add to this.

Was your mom the queen of guilt? Is this a learned behaviour for you? Did you hear the phrase, “You should be ashamed…” when you were younger?

I sure did. Certain religions, (growing up Catholic, or in my case, Pentecostal) seemed to serve guilt as an entree to life. I was taught to feel bad about everything—my thoughts, my actions, my in-actions, you name it. I never felt good enough, or that I could ever do enough.

That’s sad. I don’t believe that shame based manipulation is good for anyone, especially a child. And I don’t believe that’s what God ever intended. Guilt can lead into the downward spiral of depression. Be careful of that little buggar. Stats say that 52% of Americans experience depression—and I wonder what percentage of them are wracked in guilt? (depression.about.com/o1/factsfigures/Statistics.htm –

Sure, guilt might work for awhile, on the surface—but it doesn’t begin to touch on the issues of the heart.

Sometimes, our loved ones still employ guilt tactics to keep us entangled and paralyzed.

Ever heard these lines?

“You never come to see me.”

“Why can’t you just do this one thing for me.”

“I thought you’d be glad to…”

My mother had a purse full of guilt lines and she’d whip them out all hours of the day and night—and it didn’t matter who was around. At 89, I insisted she move in with my family and me. She had Parkinson’s, and although she wasn’t aware, the beginning signs of Alzheimer’s. I moved heaven and earth to sell my home, her home, put us all under one roof, drive her to every doctor’s appointment, find her a church she liked, buy her favorite foods, and you know what she used to tell people?

“Carol’s asked me to give up so much just to move in with her.”
Now, I can laugh. Now, I see that as her defense mechanism. Now, I see that statement as a way of her to keep her dignity, to feel in charge. I wasn’t as merciful with her at the time. I rolled my eyes and looked disgusted. And yet, I did feel guilty. Had I made the right decision?

Here you are. 30, 40, 50, or more—and you’re wracked with guilt.

Here’s something I wrote in journal several years ago as I was caring for my mother:

Letter to Self

Dear Carol, So far, you’ve been taking care of your mother for a year and a half. You’ve stuck it out through crazy times, angry times, tender times, through hospital visits and home health visits and while everyone else gets to come and go, you’ve stayed. You haven’t had a vacation and no more than two days away this whole time. I know that when your mother dies, you’re going to feel guilty. I know you. You’re going to think that you should have been kinder, less rushed, that you should have done more with her, taken her more places, insisted the kids be nicer. I know you’re going to miss her and wish that a million things had been different. I want you to know you did the best you could. You remained faithful. You grappled with every decision. You let her into your life and your home, and you and your family did what most people wouldn’t even have considered, much less done. People aren’t perfect, and if they try to be, then they’re not real. We’re not supposed to get it all right. Remember that you had to balance this with being a wife and mother. It’s only natural to want to move forward and be more interested in your children, in those who are living. That’s how the human race survives.

Remember that her emotions were always on an ever-widening pendulum and Alzheimer’s took it to frightening heights and devastating lows. You learned as a child that you couldn’t trust her with your heart although you kept trying. It just wasn’t ever possible. That’s okay. You also know she loved you and you loved her.

It really did help to write that letter to myself. To rationalize guilt away, to expose it, to learn to be tender with myself—as tender as I would to a dear friend.

Become your own friend. Talk to yourself. I do a lot of self-talks in the car. I’m grateful for bluetooths because most people just think you’re talking on the phone.

By going into “third person,” I’m able to objectively treat myself with the same respect, dignity, and honor I tend to give others.

A Few Guilt Breaking Techniques:

- Self Letters, and letters to your loved one explaining why you simply can’t fall into the guilt trap any more
- Self-talks—or talk to your loved one (metaphorically). Argue, tell them to stop. Tell them it isn’t going to work any more.
- List all the things you’ve done—with love, kindness, and commitment. You’ll be surprised how very long this list is.
- Put yourself in your loved one’s shoes. They don’t like feeling weak and vulnerable, and guilt is one of the very few tools they possess.
• List ways you “think” you’ve failed. Then really look at that list. Is this in any way realistic?
• Cut yourself some slack. Take “perfect” off the table. Be realistic. If there’s one area you, personally would really like to improve upon—then make a plan. Do it. One thing—not the whole mountain.
• Learn to let go. Whatever you didn’t do right 10 years ago, yesterday, or in the last five minutes is the past. Let it go. Keep a stone or shell in your pocket to remind you to let go of old baggage.
• Visualize guilt as a toxic bright green substance as dangerous as battery acid. Every time you have a guilty thought, see your heart being splattered with this yucky, sizzling, flesh eating gunk. Become “allergic” to guilt.
• Adopt the mentality, “If I’d-a known better, I’d-a done better.” Now you know. It’s a new day.
• Take a tube of lipstick and draw a big heart on your bathroom mirror. Align your face to fit the inside of that heart. Every day, put yourself in that heart. Smile, and say out loud, “I’m a good person, and I have a good heart.” Do this several times a day. Straighten your posture. Take a few deep breaths. Smile. Begin to view yourself as your own best friend. Your own advocate. Don’t let anyone, including your “other selves” tear down this person you love and respect.

Have a great, guiltless day!~

Carol D. O’Dell

Author of Mothering Mother: A Daughter’s Humorous and Heartbreaking Memoir,

Available on Amazon and in most bookstores

Kunati Publishing
It's a strange paradox that having positive feelings should be yet another source of selfflagellation, but there you have it. Take, for example, the caregiver I talked with recently who's been agonizing over whether it was time to place her mother in a care facility. Her mother, an obese diabetic, had incontinence that was getting harder to manage, and there were increasing signs of advancing dementia. The daughter just couldn't decide what to do. Then the mother needed a foot amputation related to her diabetes. She was discharged to a rehabilitation facility, and the transition made it clear to them both that an **assisted living facility** was a better, safer option than either's home. Providence had made the decision. The daughter was relieved...

...and yet simultaneously, pricked with guilt that she should feel relieved. "Somehow it seems like I let her down even though it worked out okay," she says.

Other places where this kind of guilt dogs caregivers:

- Using respite care, so you can get a break.
- Leaving the person in someone else's care for several days, so you can take a vacation with your family without him or her.
- Hiring regular in-home help for few hours a week (or more) to lighten your load.
- Transitioning a parent or other relative into a long-term care situation (even if everybody likes it).

Why do we feel guilty even about events that make life easier? One reason is that we're the victim of our own best intentions. We want to do our best, want to do it all, and when we can't meet our own Olympian standards (btw virtually no caregiver can, especially solo), we can't help feeling we failed a little bit. And then that pesky monkey taunts us that we therefore don't deserve a break today.

Confession: Guilt is a favorite topic of mine. And not just because I'm so ace at feeling it. For years, covering the parenting end of the family beat, I've interviewed everyone from Drs. Spock, Brazelton, Sears, and Karp to researchers, psychologists, and most importantly, countless mothers. (Talk about the **real** experts in guilt!) It's amazing how often the topic of guilt bubbles up. And it strikes me that much of what I learned about mom guilt transfers to caregivers of adults—including this curious phenomenon of guilt over cutting ourselves a break.

**Some rules of thumb about guilt:**

- **You can't ignore this pesky emotion, can't will it away.** Guilt simply is. So straight off, don't think there's anything bad or wrong about your feeling it.

- **There's good guilt and bad guilt.** **Good guilt** is the kind that causes us to examine our behavior and make a change, if necessary. If you feel guilty because, say, you were impatient with a parent with dementia, it's like a little poke reminding you to try a little harder next time because hey, patience really is a virtue. Unfortunately what eats most of us alive is **bad guilt.** Bad guilt has no constructive underbelly. Bad guilt makes you feel guilty about a situation that you can't help (your

http://www.caring.com/blogs/caring-currents/caregiver-guilt
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parent has to move into rehab, for example) or that is actually a positive for you (you're hiring home care because you can't do it all yourself).

- **Beware the oughts-shoulda-couldas.** For caregivers, this refrain can sound like: "I ought to be able to handle this; I'm her daughter." Or, "I shouldn't feel so happy about going someplace without Dad." Or, "I could have handled that better." Things (and feelings) are what they are; stewing or denying wastes precious energy.

- **Guilt creeps in when we discount ourselves.** Ironically, selfless people tend to feel proportionately more guilt. Because they work so hard aspiring to an ideal way of doing things for others, they tend to ignore the inconvenient reality that they have to look after themselves all the more. They may even forget that they, too, deserve extras and shortcuts. Or, when they finally get around to (by choice or force) having a Calgon bath or lunching out with friends, it feels as alien as it does great. That's a sign you probably need to follow your self care with more self care.

- **Guilt loves high standards.** News flash: Nobody's perfect. No caregiver anticipates every fall or bed sore. Tempers boil. Germs sneak in. Bills slip through unpaid. Life happens, in other words, no matter how much you love the person or how much you feel you "owe" him or her. Aim to be a "B" caregiver instead of an A+ caregiver, and everybody's going to be happier.

- **No mom is an island. No caregiver, either.** I think it's no coincidence that most of the "happy guilt" that creeps into a caregiver's mind follows having the load lightened by getting help. It's such a persistent canard that it's somehow a sign of weakness to ask for or find assistance, and from as many [sources of help](http://www.caring.com/local) as you can locate or who will offer it.

As I write this, I'm resisting that childrearing cliché, "it takes a village," with all my might. But I bet those villagers (parents, caregivers, whomever) are not only happy – but less guilt-ridden, too.

See all posts in "Caring Currents"

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**Retirement Shock: How to Get Back on Track When Your Savings Are a Shambles**

**Bad News for Menopausal Women: Hormone Therapy Boosts Ovarian and Breast Cancer Risk**

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