

Caregiving and Guilt

Care Partner Tool Kit

When one cares for a family member or loved one with a chronic illness or disability, we want to do everything possible to give our carees the best care and the best quality of life.

But a disease continues to progress. Our carees continue to age. As care partners, we encounter challenge after challenge trying to ensure the best care and quality of life.

We may feel discouraged, frustrated, and overwhelmed when our efforts to provide the best care and create the best quality of life seem to come up short.

And, then the guilt settles in. We may feel guilt for several reasons, including:

- We have good health as our caree's health declines. Because of our good health, we can do what our caree can't.
- Our life moves forward as a caree's life seems to be derailed by an illness or injury. Moving forward can feel like leaving a caree behind which could tempt us to stop our own forward motion so we can keep a caree company.
- We lose our patience because we run out of energy and good temperament during our draining days. When we lose our patience, guilt tempts us to believe we are sinners unworthy of forgiveness. We believe we should be doing better even as we do our very best.
- We have difficult thoughts about how much a caregiving experience impacts us. We may flirt with bitterness and resentment about the sacrifices we make. We then beat ourselves up for losing faith.
- We have guilty feelings about wanting our caregiving responsibilities to be over. We so want the pain and suffering to end for ourselves and our carees. We then feel guilty that it seems we wish for our caree's death which lures us into the belief that we are awful for having such thoughts.

Guilt can intensify an experience that already overwhelms. During our caregiving experience, we navigate, manage and advocate within [17 Caregiving Systems](#), including the health care system, the medical system, the family system and two nervous systems — ours as well as our caree's. According to [The Caregiving Years Training Academy](#), family caregivers rate their stress level at 4.12 on a scale from 1 to 5, with 5 being the most stressed.

As family caregivers, we feel for two — for ourselves and for our caree. As we feel for two, we understand how our choices, decisions and actions will impact our carees.

We also feel our caree's frustration and sadness over their losses — a loss of independence, good health, and connections to who and what they love as their illness makes their world smaller. Thoughts about our caregiving responsibilities may be what send us on our most difficult guilt trips.

Care Partners Share About Their Guilt

In The Academy's ongoing stress survey, family care partners share their thoughts about their guilty feelings, and this is some of what has been shared:

- My own feelings of guilt like I SHOULD be doing more. I SHOULD always be happy to help. I SHOULD not be frustrated with requests for help, with I'm doing something else. I SHOULD be so happy that I have a sweet, wonderful mother that made me feel loved and I should NEVER have bad thoughts about the responsibility of caring for her. I am frustrated that the majority of my mom's care falls on my shoulders and people do not offer to help, unless I ask them for one specific thing after another. My sister does not help as much as she can, because she is easily frustrated by our mother's requests, her voice, her questions about her personal life, her neediness. My niece and nephew are busy with their own lives and don't call my mom enough, so she's lonely. She lives alone still but does need company and help with simple tasks. I don't trust the caregiving services that exist — what if they are mean to my mom, what if they steal from her, what if they take advantage of her?
- Struggling with the catch 22 of the only way that I get things back to normal, which is what I think I want the most, is for my dad to pass, which I don't want. I feel tremendous guilt whenever I look forward to getting back to normal.
- The guilt I feel for wanting it to end so I can move on with my life without being responsible for someone else. I feel like I spend 80% of my time caring for others and I'm exhausted.
- Guilt — so much guilt. Not spending enough time with caree and then losing patience with her when I do.

We often believe we should not feel as we do so we often deny our thoughts which means we cannot receive the support we need to release these difficult thoughts. We may believe our difficult thoughts, which truly reflect the overwhelming reality of our experience, mean we are not deserving of forgiveness or compassion.

Our guilt also speaks to our challenge in managing pain and suffering experienced by ourselves and our carees. We may believe if we withhold from ourselves, we can balance the scales so that our caree feels better. For instance, a family caregiver may feel if she remains at home with her mother rather than getting a break by spending a few hours with friends, then her mother will feel better about her own circumstances.

If we sacrifice, then it seems to make sense that our caree will feel better. If we believe statement that then, we also could believe that if we feel joy then our caree feels worse.

In truth, if we sacrifice too much, including opportunities to be happy, then we create a miserable experience for ourselves and our carees. If we allow ourselves time for what brings us joy, then we feel happiness which creates a more pleasant environment for everyone. When given the choice — misery or joy — everyone will choose joy.

During a difficult time in her life, the pastor of a family care partner told her: God wants you to be happy. During a caregiving experience, God wants us to be happy as often and as much as we can.

Our Faith Comforts Family Care Partners and Carees

In our faith, we can know that God comforts us and our carees. We don't have to take on the role of Chief Comforter for our caree and in doing so give up opportunities for us to enjoy life. God comforts all of us, especially our carees.

If we believe we are the only ones who struggle with guilt, we may remain silent about our guilt. We can encourage a conversation about our guilt by reading Scripture readings that remind us that God listens and forgives. We can release our guilt when we remember that our faith means we are forgiven. In addition, Scripture can remind us that God is our constant companion who offers love and solace to our caree. We can feel so alone during our caregiving experience; regular reminders of God's presence can lessen that loneliness.

Some scripture readings that may be helpful to care partners include:

(These are from the NRSV Updated Edition, but one may also find another translation helpful.)

Isaiah 41:10

Do not fear, for I am with you; do not be afraid, for I am your God; I will strengthen you; I will help you; I will uphold you with my victorious right hand.

2 Corinthians 1:3-4

Blessed be the God and Father of our Lord Jesus Christ, the Father of mercies and the God of all consolation, who consoles us in all our affliction, so that we may be able to console those who are in any affliction with the consolation with which we ourselves are consoled by God.

Psalms 119:50

This is my comfort in my distress, that your promise gives me life.

John 16:20

Very truly I tell you, you will weep and mourn but the world will rejoice; you will have pain, but your pain will turn into joy.

John 16:33

I have said this to you so that in me you may have peace, In the world you face persecution, but take courage: I have conquered the world!

Romans 15:13

May the God of hope fill you with all joy and peace in believing, so that you may abound in hope by the power of the Holy Spirit.

Romans 8:28

We know that all things work together for good for those who love God, who are called according to his purpose.

Job 5:11

He sets on high those who are lowly, and those who mourn are lifted to safety.

Ecclesiastes 3:1-8

For everything there is a season and a time for every matter under heaven: a time to be born and a time to die, a time to plant and a time to pluck up what is planted, a time to kill and a time to heal, a time to break down and a time to build up, a time to weep and a time to laugh, a time to mourn and a

time to dance, a time to throw away stones and a time to gather stones together, a time to embrace and a time to refrain from embracing, a time to seek and a time to lose, a time to keep and a time to throw away, a time to tear and a time to sew, a time to keep silent and a time to speak, a time to love and a time to hate, a time for war and a time for peace.

Romans 8:37-39

No, in all these things we are more than victorious through him who loved us. For I am convinced that neither death, nor life, nor angels, nor rulers, nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation will be able to separate us from the love of God in Christ Jesus our Lord.

Psalms 119:76

Let your steadfast love become my comfort according to your promise to your servant.

Isaiah 61:1-2

The spirit of the Lord God is upon me because the Lord has anointed me; he has sent me to bring good news to the oppressed, to bind up the brokenhearted, to proclaim liberty to the captives and release to the prisoners, to proclaim the year of the Lord's favor and the day of vengeance of our god, to comfort all who mourn.

Isaiah 66:13

As a mother comforts her child, so I will comfort you; and you shall be comforted in Jerusalem.

II Corinthians 5:21

For our sake God made the one who knew no sin to be sin, so that in him we might become the righteousness of God.

Ephesians 1:7

In Him we have redemption through His blood, the forgiveness of trespasses, according to the riches of his grace.

1 John 1:9

If we confess our sins, he who is faithful and just will forgive us our sins and cleanse us from all unrighteousness.

Hebrews 8:12

For I will be merciful to their toward their iniquities, and I will remember their sins no more.

Create Meaningful Connections

When people gather in a safe, trusted space, they can share honestly about their caregiving guilt. Some ideas to help faith communities provide these meaningful conversations and connections include:

Releasing Guilt Exercise

During our caregiving days, we manage intricate tasks, never-ending challenges and sensitive interactions. In our mind, we must achieve with success and a smile. We fail if we manage to show our humanity by being short-tempered or impatient or humorless.

We feel guilty for being what we are -- human. Let's take a closer look at how guilt shows up for you. Consider: What does guilt feel like to you? When do you feel guilty?

Thoughts -- like I shouldn't have a life, be happy, get a break, feel trapped, be impatient, get angry, feel resentment -- can start our guilt trip.

Because our guilt can begin with *shouldn't*, let's start to heal by turning *shouldn't* into *possible*. Even when our life feels like a perpetual winter, we can still find growth. We can still give ourselves a chance to become better. Take a moment to consider the following questions and then complete the corresponding statements.

Consider: What's possible? What's possible for your personal growth?

I can _____ to fuel my personal growth.

Consider: What's possible for your spiritual growth?

I can _____ to fuel my spiritual growth.

Consider: What's possible for your professional growth?

I can _____ to fuel my professional growth.

Consider: What's possible to improve your relationship with your caree?

I can improve my relationship with my caree by _____.

Consider: What's possible to improve your relationships?

I can improve my relationships by _____.

Consider: What's possible that can improve your day?

I can _____ to improve my day.

November Conversations

During November, which is [National Family Caregivers Month](#), faith communities or individuals can host a weekly conversation called "How Our Faith Can Heal Our Difficult Caregiving Emotions". During one of the meetings, you can focus on guilt.

During a gathering about guilt, you can use these questions to guide the discussion:

1. What does our faith say about feeling guilty?
2. How can our faith help us release guilt?
3. What prayer can we say when we start to feel that we "shouldn't" take a break, or enjoy life or spend time away from our caregiving experience?
4. You also share the Releasing Guilt Exercise.

Weekly Bulletin or Newsletter Messages

The weekly bulletin or a newsletter provides opportunities to include comforting messages that remind worshippers that they are worthy of forgiveness, joy, and comfort. Their humanness does not exclude them from this worthiness. Instead, they are human, which means they have difficult thoughts and experiences which makes them worthy of forgiveness.

Comfort for Carees

When your congregation remembers those with disabilities, illness, or injury, you remind care partners (family/loved ones) they have support. When you help a caree, you support a care partner. Initiatives you can sponsor to offer comfort include:

Prayer Circles

- Volunteers gather in-person or virtually on a regular schedule to pray for both carees and care partners.
- Volunteers regularly send cards to carees to remind them that the prayer circle keeps them close in prayer.
- Volunteers make phone call carees to say prayers together.

Quarterly in-person Worship services for care partners and carees

- During these special services, volunteers help so the caregivers and carees have support to ensure they can enjoy the service.
- You can adjust the service to accommodate those with special needs and those who dementia.

Monthly virtual Worship opportunities for care partners and carees

- Consider hosting monthly virtual services so that care partners and carees conveniently connect to their faith and their supportive congregation.
- A small group or bible study group is another option.

Host Care Partner support group

- Learn about starting a support group from the How to Guide Quicksheet which is part of this [Care Partner Tool Kit](#).
- Offer your space to other organizations which have support groups.

When an individual or faith community takes any action to support care partners, they demonstrate a commitment to being of service to the care partners and carees. With that act of service, care partners feel seen and understood which in turn relieves their guilt.

Helpful Resources

- *Healing Words: Soothing Strategies for Your Caregiving Fatigues* by Denise M. Brown
- Free courses on CaringOurWay.com, a community of support for caregiving and after caregiving, include:
 - Healing Our Caregiving Fatigues, a 12-part course, includes a workshop on releasing guilt.
 - The Daily Recovery Plan helps family caregivers recover after a difficult caregiving day, a draining caregiving crisis or overwhelming caregiving situation.
- *Self-Care for the Caregiver: A Guilt-free Way to Love Yourself While Caring for Others* by Maydis Skeete.

This Quicksheet is part of the [Care Partner Tool Kit](#) where you can find additional Quicksheets on other Care Partner topics and a Resource Roadmap with websites and books. For additional resources see, the resource library page for the partners in this project [POAMN \(www.poamn.org\)](http://www.poamn.org) and [APCE \(www.apcenet.org\)](http://www.apcenet.org) or the [Office of Christian Formation \(www.pcusa.org/formation\)](http://www.pcusa.org/formation)

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