

# PRESBYTERIAN VILLAGE NORTH

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## FOREFRONT LIVING



### **Dementia Live® Empowerment Tool for Understanding Caregiver Guilt**

The journey of caring for someone with dementia could include moments of feeling guilt. Guilt is a normal emotion, but steps can be taken to avoid it from becoming paralyzing or obsessive.

#### **TIPS FOR RESPONDING TO FEELINGS OF GUILT:**

1. **Identify your feelings.** Guilt is a complex emotion and can reveal itself in varying ways. The source of your feelings may stem from: something you did, or perceive you did; something you did not do but want to; that you did not do enough for someone else; or that you are doing better than someone else (survivor's guilt). Caregiver guilt mostly arises from our beliefs that we should be doing more or better, and/or survivor's guilt.
2. **Determine if your feelings are rational or arbitrary.** Feelings come from our thoughts and experiences. More often than not, caregivers experience arbitrary thoughts that lead to arbitrary guilt. For example:
  - I should be visiting my mother every day at the nursing home
  - If I had been there, he wouldn't have fallen
  - There has to be something more I can do to make her happy

Sometimes, the relationship history with our care-partner can get in the way. If you experience rational guilt based on the past, it may be helpful to get it out in the open.

3. **Acknowledge and accept your feelings as normal.** Feeling guilt is normal, but letting those feelings overtake your life is not. Practice self-awareness to identify the presence of obsessive negative thoughts.
4. **Frame realistic expectations of yourself.** Caregivers can only do the best that they know-how. Forgetting a doctor's appointment or paying a bill on time does not make you a failure at being a caregiver. Helpful reminders to yourself may include:
  - Regardless of what I do or don't do, I cannot prevent my loved one from declining.
  - I did not cause or create this situation.
  - I am doing the best that I can.
5. **Understand Familial Responsibility.** In most cultures, some care for elderly parents by adult children is generally expected. Most feel that adult children owe something to

their elderly parents, but it is not always clear what children are supposed to do. Researchers Maria C. Stuifbergen and Johannes Van Delden conclude, “Our familial obligation regarding care for elderly parents is to maintain the relationship, and by maintaining contact, trying to be sensitive to one’s elderly parents’ needs.. to care about our parents.” Familial responsibility does not include the sacrifice of happiness, independence, or relationships for the sake of taking care of our parents.

6. **Acknowledge and honor your right to quality of life.** It is helpful to consider caregiver quality of life from the perspective of the parent. Most parents would not wish for their child(ren) to suffer or forsake their happiness on their behalf. Elderly living with dementia may act differently. The disease takes over rational thought, and many caregivers have been the target of hurtful, devastating comments, and behaviors. Remember to separate the person from the disease, and don’t permit disease-driven comments to undermine your quality of life.
7. **Develop a healthy caregiving life philosophy.**
  - Love without losing yourself
  - Don’t sweat the small stuff
  - Focus on the good that you are doing
  - Be compassionate with yourself
  - Accept that you cannot and should not be on this journey alone
8. **Seek professional help if thoughts and feelings are overwhelming.** If you find yourself living with chronic guilt feelings that interfere with your life, please seek professional help.

**You will be a more effective caregiver when you care for yourself first.**