

- Barry J. Jacobs, Psy.D.
- Julia L. Mayer, Psy.D.
- The AARP Caregiver Answer Book
- www.caregiveranswerbook.com

7 Tough Questions That Worry Dementia Caregivers



TODAY'S CONVERSATION

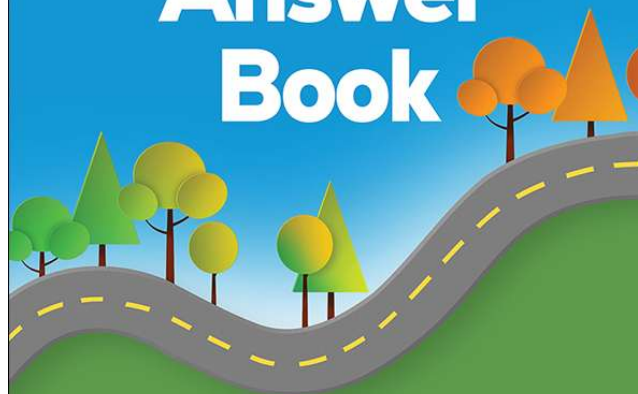
- Caregiving in America 2025
- Seven common questions about determining your commitments, managing stress, gaining others' cooperation, communicating with doctors, and more
- What questions would you like to discuss?





"Inspiring, reassuring, and easy to read."
—Katy Butler, bestselling author

The AARP Caregiver Answer Book



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Family Caregiving in America

- 63 million Americans engage in some form of caregiving activity in a year (NAC/AARP, 2025)
- Sandwich generation: 27% (unpaid)
- 47% for parent; 15% for spouse; 11% for non-relative; 8% for grandparent; 6% for adult child




Effects of Caregiving on Family Caregivers

- **Positive:**
- Enhanced sense of purpose through “giving back,” “doing the right thing,” “doing God’s work in this world”
- **Negative** (esp. for **dementia**, spousal, and military caregivers):
- Increased stress → higher rates of depression/anxiety
- Loss and grief
- Poorer overall health




From Wife of Alzheimer's Patient

- *"I don't think anyone can understand the intense, crushing isolation and loneliness of caregiving unless they have 'walked a mile in our shoes.' I miss the intimacy we've had for more than 50 years, and I'm not talking about physical intimacy, although I miss that, too. I miss having someone to talk to or share a chuckle or one of our little 'inside' jokes. It's all gone! I'm not ready to ditch my marriage vows and dash out and have an affair, but I long to have a companion again--even someone to just stand and hold me while I cry the tears I've had to squelch and swallow for so long."*—comment on AARP.org


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- My mother was just diagnosed with dementia. I don't really know what I'm supposed to do to help her. How do I figure this out? I don't want to mess this up.

- Everyone feels unsure at the beginning. **Everyone makes mistakes.** Doesn't mean you will mess it up
- **Educate yourself** about mother's condition, prognosis, treatments and their side-effects, support services, other resources
- Estimate mother's needs now and in the future
- Determine your **availability, ability, and willingness**
- Your job isn't to provide all care yourself. It is to **help ensure your mom is well cared for**—perhaps with help of others or hired help


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- I don't want to tell my husband what to do all the time, but I need to keep him safe. How do I also help him keep his independence and dignity?




- Refusing help may be your spouse's way of saving face and holding onto his identity as a capable adult.
- **Lead with empathy** about the losses he is experiencing
- Gently offer help.
- Try to **preserve reciprocity**
- As empathic and gentle as you may be, your husband may not stop being angry about being in dependent position and direct that anger at you

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- A thick yellow vertical bar on the left side of the slide, with a horizontal extension at the top.
- I hear I'm supposed to have a caregiving team but I don't think I can work with my brothers. One doesn't believe Dad has dementia and won't help me. The other criticizes me all the time for the decisions I make. How do I get them to cooperate with me?


- Not uncommon for conflict to arise among adult siblings
- Two types of challenges: **siblings who don't help and those who want to control the caregiving plan**
- Consider three-part plan:
 - Meet (possibly with facilitator) to **create greater consensus** about the care receiver's condition and needs.
 - **Create a caregiving plan** in which everyone has a role, though roles will be different and unequal.
 - **Create a process to review the plan**—e.g., meeting quarterly to update plan as care receiver's condition changes and caregiving team members' life circumstances shift

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- No matter how much I do, I still feel guilty for not doing enough or doing the wrong thing or not keeping my older brother happy. How do I get rid of all this awful guilt?

- **Goal should be decreasing intensity of guilt**, not eliminating it
- As long as the people we are caring for are suffering, then we are likely to suffer, too, and have some guilt that we can't relieve their suffering entirely
- **Cognitive behavior therapy** techniques are helpful for identifying unrealistic expectations for yourself so that you stop judging yourself so harshly
- All caregivers make mistakes, especially early on. **We need to extend grace to ourselves** and others

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- My friends tell me I should take time for myself, but they don't understand how much I need to do. Besides, if my wife can't go out and enjoy herself anymore, then how could I?


- Nearly 80% of caregivers say they are stressed or highly stressed; less than 20% say they have no stress (NAC/AARP, 2025). **Feeling stressed is a normal part of caregiving.**
- Self-care is essential for helping sustain yourself over time to fulfill the mission you've set for yourself. Its form depends on whatever you have always done to replenish yourself, but **requires willingness to pursue those activities with a minimum of guilt**
- Caregiver as marathon runner. Need to pace yourself, take a water bottle at each water station, and run alongside others

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- A yellow decorative graphic consisting of a vertical bar and a horizontal bar at the top, forming an L-shape.
- My care receiver's doctors don't always listen to me. They think they know more about my care receiver than I do. How can I get them to respect me and allow me to become a partner in the care?

Partnering with Healthcare Professionals

- Offer dignity, preference—but not necessarily deference
- Make yourself a valuable team member
- Respect care receiver's rights to limit the conversation
- Expect reliability, attention, and respect from physician—or seek another provider



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- Once caregiving is over, how do I bounce back? I just want to go back to the life I used to have. Is that possible?

- **Caregiving changes caregivers.** Most of the time, they don't want to go back to the lives they had before. They often want to take what they've learned during caregiving and to **make good with it in their post-caregiving lives**
- Examples include former caregiver who becomes hospice volunteer, caregiver for other family members, or formal or informal caregiver coach to help new caregivers

Your turn

- What's on your mind?
- What questions about caregiving do you have?





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Our caregiver self-help books

