



Engaging Your Family in the Caregiving Journey

Barry J. Jacobs, Psy.D.

Health Management Associates



Today's Talk

- Two types of advocacy
- Advocating for yourself with your family
 - Dealing with triple guilt
 - Grappling with family history and dynamics
 - The advantages of teams
- Advocating for other family caregivers

CHAT: Do you provide care to a relative by yourself or in coordination with other family members?

- **Options for answers**

- 1) I'm the primary and sole caregiver. It's 100% on me.***
- 2) I'm the primary caregiver and others help me a little***
- 3) I'm the primary caregiver and others help me a lot***
- 4) In my family, we divide the caregiving tasks up equally***
- 5) I help the primary caregiver a lot***
- 6) I help the primary caregiver a little***
- 7) I don't help the primary caregiver at all but am considering it***

Introduction

- **advocacy**
- noun
- ad·vo·ca·cy 'ad-və-kə-sē
- the act or process of supporting a cause or proposal

Caregiver As Advocates...

- Actively support themselves and others
- Use assertiveness skills
- Engage in problem-solving
- Manage situations, not feel controlled by them
- Feel effective and helpful, not ineffectual and unhelpful
- Maintain hope



A group of seven people, including adults and children, are gathered outdoors at dusk. They are standing around a wooden table set with food and drinks. The scene is dimly lit, with a warm glow from the setting sun. The background shows a brick wall and some foliage.

Advocating within Your Family

The Taylor Family

- Since her father had a mild stroke several months ago, June, 41, has been taking care of him at her house.
- Her two older brothers call occasionally but don't offer to help her with the caregiving tasks
- She is tired and needs help





“Why should I have to ask my brothers for help? Dad is their father, too. They should be here for him—and me.”

- Do you think June is right?
- Should she continue to expect that they’ll step up and assist with caregiving tasks, or should she ask them directly?
- Why might she be afraid to ask them for help?



“My Dad is old-fashioned and thinks caregiving is women’s work. He trusts me and wants me, not his sons, to help take care of him.”

- Should June go along with her father’s wishes to make him more comfortable?
- Is it okay if she wants help for herself, even if Dad says he will feel embarrassed if his sons or home health aides help take care of him?
- Do you think she’ll feel guilty?




“It’s just easier if I do everything myself.”

- Perhaps June doesn’t want to bother her brothers because they have busy jobs and lives. Perhaps she doesn’t want to put herself in a position in which she’ll feel aggravated if they say no or don’t provide the kind of help that she thinks Dad needs.
- Do you think June is right to do everything herself?
- What are the advantages of doing all the caregiving herself?
- What are the disadvantages?



Triple Guilt

- 
- Care receivers judge caregivers who don't meet their expectations to take care of all their needs
 - Family members make judgmental comments that make caregivers feel guilty that they aren't doing enough
 - Caregivers judge themselves harshly if they disappoint care receivers or family members

How We Can Talk Back to Guilt

- ***“I’m doing the best I can. There is no shame in that.”***
- ***“Others don’t get to decide what I should do. I get to decide that, just as any other person does.”***
- ***“Sometimes I’m too hard on myself. Self-criticism doesn’t make me a better caregiver. It’s like rubbing salt in my own wounds.”***



- ***What do you say to yourself to manage your guilt?***
- ***How helpful is it?***
- ***Do you just accept guilt as an inevitable part of caregiving?***

Dealing with Family Dynamics

- Families have patterns of communication, decision-making, and collaboration (or lack of it) and roles based on age, gender, history, etc.
- ***How should June account for her family's dynamics as she reaches out to family members for caregiving help?***



Family Dynamics (cont.)

Tailor your asks

What: Tasks should be well-defined and specific in time

Who: Know who is most likely to agree to which task

How: Using the words and tone that family member can hear. Alone or in a group setting? In person or via text?

When: Pick your spots. Be aware of the family member's stress level at different times.

Caregiving Teams Have Advantages...



- Less pressure on primary caregiver
- Talents and energies of multiple caregivers
- Decreased burnout
- **...and disadvantages:**
- Divvying up roles
- Coordinating caregiving efforts
- More people, more opinions, more disagreements

Qualities of Working Teams

Trusted leadership

Specific roles for
team members

Communication
process

Decision-making
process


Process for
reviewing and
revising team
processes

- ***Do you have a caregiving team?***
- ***What processes do your team members use to work together?***
- ***How well does the team perform?***

Rules for Assembling Your Team

- Don't assume any or all family members will step up. Ask specifically with discrete roles or tasks.
- Teams work best if there is one or two primary caregivers
- The division of labor among team members will never be equal
- Not all help is helpful. Give long-distance caregivers helpful roles.
- Revise the caregiving plan at least quarterly in response to changing needs—the care receiver's but also all team members'.





Advocating for All Caregivers

- ***What do you do to help other caregivers?***
- ***How does that help them?***
- ***How does that help you?***



Reaching out to Other Caregivers

- Sharing your experiences with others in your community or on online platforms such as a caregiver Facebook group or advocacy group (e.g., Caregiver Action Network, Rosalyn Carter Institute, Well Spouse Association)
- Starting a caregiver support group at your church, local hospital
- Becoming a caregiver mentor



Reaching Out to Policymakers

- Share your feedback with service providers—customer satisfaction surveys, needs assessment, input on on quality improvements
- Raise public awareness through articles, presentations
- Let public officials know that caregivers need more support
- Attend public hearings on caregiver initiatives and make comments verbally and in writing
- Volunteer for a national caregiver advocacy or disease-specific organization

- ***What other ideas do you have for advocating for other caregivers?***

*Thoughts?
Questions?*



- Barry J. Jacobs, Psy.D.
- Principal, Philadelphia Office
- bjacobs@healthmanagement.com
- 267-408-6456



