



Caregiver self-care: Dealing with burden, preventing burnout

Kathryn Betts Adams, MSW, PhD

Being a caregiver to a family member with Alzheimer's disease, chronic physical conditions, or simply old age and increasing frailty is hard and sometimes heartbreaking work. According to research from AARP in 2015, about half the time, there is just one family caregiver handling everything, and if the person needing care is your spouse, that rises to three quarters of the time. And in nearly every family, there is a primary caregiver – the spouse, a particular grown child, grandchild, or sibling – the one who takes the lead and performs most of the caregiving tasks.

As the primary caregiver, you may find that you need to do more and more to keep your care recipient safe and well cared for. Perhaps you've moved your parent into your home, or you have to stop by their home several times a week to check up and help out. You drive them to doctor's appointments and spend odd moments on the phone making arrangements. You buy their groceries and pick up their medications. You have to make decisions and get the help and supervision your family member needs.

Yes, caregiving is time-consuming and energy draining. The resources to help may be out there, but they are difficult to navigate and evaluate. And your family, like many families, may hesitate to bring in professional or hired helpers, believing you "should" keep things as normal as possible, not rock the boat, and try to do everything within the family. So you end up adding all these new duties and worries into the regular obligations and responsibilities of normal life.

People tell family caregivers to take care of themselves, but realistically, how? What should you do?

At Assured Allies, we advise caregivers to keep four things in mind:

- 1. Establish your informal Care Team**
- 2. Pace yourself**
- 3. Respect your own needs**
- 4. Consult with experts and others you trust.**

Let's elaborate a bit on each of these.

No man (or woman) is an island, and no caregiver should be, either. Sooner rather than later, you must reach out for help and support. And keep reaching!! Get a Care Team together and keep them involved.

Do not fall into the "only I can do this" trap. DELEGATE. It's not at all uncommon that the care recipient, your wife or husband, mother, or brother, wants ONLY YOU to be there and do things for them. He or she probably doesn't feel good, may be easily upset, angry, or demanding. And many of us WANT to be that one caregiving person, because we love our care recipient and we know them better than anyone. But - repeat this as many times a day as necessary: It is not disloyal, selfish, or in any way wrong for you to ask others to step in, whether family members, neighbors or friends, or hired caregivers.

Call upon out-of-town family members – and don't wait till they offer! Ask them to come to town for a few days every couple of months. Set the dates with them and hold them to it. While they visit, you will be freed up to leave town or stay around and get some other things done. In-town family members or good friends who work could be enlisted to participate for an evening or weekend day. And if they do offer, say yes!

Your older teens or grown kids in the area who are "living their own lives" and whom you "hate to bother?" You know what? If they are reliable and able-bodied, get them on your team. They can spare a couple of hours a week to sit with their grandparent, go to the grocery store, or do other chores. They will be more understanding of what you are going through after they have spent some time doing what you do and gain valuable life experience.

Pace yourself

Caregiving is a marathon, not a sprint. Try to make some extra room in your schedule so you are not simply adding your new caregiving tasks on top of everything else.

Set priorities. Learn to say no, or "not now," to your care recipient, and anyone or anything else, when things are not critically necessary. Learn to leave some things for another day.

Do not expect perfection from yourself. Lower unrealistic expectations. Simplify routines and use available resources as much as you can. Is your dad truly unable to eat the meals from Meals on Wheels, or is it possible he could learn to like them and even enjoy the visits?

Be flexible and open to change. Old age and chronic conditions like Alzheimer's disease are progressive, so your care recipient's needs change over time, and so should your care plan. Work with family, health providers, and professional care providers on your team to continue to update your plans for meeting your care recipient's needs.

Respect and care for yourself

Everyone needs nurturing and nourishing, body and soul, to feel good, maintain health, and do good work. As the caregiver to a family member, this is especially true.

Every day, try to get the sleep and nutritious meals that will fuel your body well.

Every day, prioritize getting some "me time"; 30-45 minutes of doing what you enjoy, whatever that may be.

At least every few days, get some exercise, and arrange for some free time to do something that recharges your batteries.

Protect your physical health. Don't ignore your own medical appointments, check-ups, dental visits, and so on. Pay attention to signs that you are overdoing it. Learn the best ways and tools available to assist someone with transfers, toileting, or bathing without risking strain or injury. And when you can't do it alone, get help.

Build a network of experts and people you trust

Caring for a loved one, can often feel lonely, and may not be something even your closest friends can relate to in a way to makes you feel understood. That's why it is critical to develop a community you can trust to both gain perspective, and sometimes, simply vent your frustrations.

Seek out caregiver support organizations for meetings, online forums, or therapy groups. Sharing your experiences with others who are in the same boat can be very comforting and therapeutic and helps to grow your care network of support.

Talk to professionals in the industry who might be able to give you additional ideas or help you put together a plan. Aging Life Care Professionals help families navigate the challenges of caregiving and bring deep knowledge and often, personal experience with them.

Wherever you may be on your own caregiving journey, know that it is never too early (or too late) to make sure you care for yourself.

