Caring for Someone Else: Support for Care Partners

Taking care of another person is strenuous and stressful, no matter how long and loving your relationship. Some people feel trapped in their own homes, unable to leave because the person they’re caring for is not safe alone or because they get anxious if he or she is away more than a few minutes. In some situations, a person’s sleep is interrupted frequently by the needs of the person who is ill. This continual tiredness adds to the stress and inability to think clearly. It may be hard not to get annoyed when well-meaning friends say “take care of yourself,” but it is good advice. Who will be there to care for your loved one if you get sick? Taking a break on a regular basis may help you to keep going, as can nutritious food and adequate rest. Here are some ideas about how to find that break or “respite.”

A positive approach to respite care will be the first step to success. Many people have found that:

1. Having a few hours to call your own is not a selfish act. It is wise and healthy to maintain other interests, relationships, and to have fun.

2. When finding a provider, you may have to make a lot of phone calls, spend time on hold, or call back several times. Be patient and persistent. Some community organizations have staff who can help you prioritize these calls. In the Denver metro area, call Aging & Disability Resources at 303-480-6700.

3. None of the respite options will be ideal. It may be the case that no adult day care program or hired helper will provide care to your standards. No arrangement of care-sharing will fit perfectly into your routine. Use whatever is available anyway. The more demand there is for respite care, the more options we will have.

Resist the temptation to compare respite care options with what your loved one might have preferred earlier in life. That was then; this is now. Instead, compare today’s choices with the person’s current state.

Make two long-range plans -- one which assumes you will stay in good health; the other in case you become incapacitated yourself.

Become familiar with sources of information and support in the community, such as local support groups, Aging & Disability Resources 303-480-6700, rec and senior centers, Meals on Wheels or other social service agencies. Keep a notebook with as many resources as you can find and get acquainted with them even if you don’t think you’ll need them.
Visit an adult day program -- these are day centers staffed with trained professionals who provide care and socialization to your loved one while you take a break. The National Adult Day Services Association is a resource for helping you find a center and also has a checklist of what to look for when you visit: www.nadsa.org/consumers/choosing-a-center/

Give your family and friends information about the disease or condition of the person you’re caring for. Start by holding a meeting -- away from the individual needing care -- with all invested parties living in your area. Begin with a direct conversation about the person’s needs and your role in the care. Ask what people can contribute and draw up a plan of care. Things to consider in your plan of care may include:

- Current and anticipated needs
- Strengths and supports that already exist
- Prioritize goals such as socialization, accompaniment to doctor appointments, or meal preparation and then list who will do what and starting when

Once you have a tentative plan of care, do what you can to set everyone up for success in their tasks. Be sure to invite the people caring for the individual to spend time in his or her home prior to committing to respite care.

Be creative. When people offer to help, think of ways they can be helpful. Freeze-ahead meals, shopping, errands, dusting and vacuuming are easy, non-threatening things you could ask for that could free up some time for yourself. Even though you will still need to arrange for care, at least you won’t be using that precious time for chores. If someone can’t participate personally, perhaps he or she can help pay for professional respite care. Learn to respond quickly to every offer of help with a positive suggestion, a time and a date. It is always harder to call someone back later to set something up.

Your loved one may reject the alternate help at first. A positive, matter-of-fact attitude on your part will help to establish the climate that this is "okay." Don’t give up too quickly. Make sure the helper or worker understands about the way the disease affects your loved one. Try different things, such as a few prior visits with you staying there. Help the new person to interact effectively with the person. Eventually you will all adjust. If not, don’t assume your loved one will reject everyone. Keep trying. This goes for adult day programs outside your home as well. Wait a few weeks and try again.

Piece together a plan when there are no easy or affordable solutions. Two or three families can sometimes share one full-time worker. Or you might start an informal "co-op" such as a Tuesday/Thursday coffeeklatch of four care receivers and two rotating pairs of helpers. If there are scheduling problems with an adult day program, there may be a neighbor willing to fill in the gap time or provide transportation.
Respite Care Options:
Adult day programs, church and service organizations, in-home health agencies, friends and neighbors, family members, volunteers through community organizations

Later On:
Assisted living, skilled nursing facilities, live-in helpers

Other Help:
Aging & Disability Resources, grants for respite from the Colorado Respite Coalition, Meals on Wheels, chore service agencies, social workers at your doctor’s office

Keeping you -- the person providing care -- healthy is of higher importance than "not pleasing" the person needing care or compromising your standards for short periods of time. After all, if you burn out, what will the care be like then?

Terms to Know
Caregiver vs. Care Partner?
The terms we use to describe one person caring for another person matter. Often, the term “caregiver” has been used to describe someone caring for a person who has a disability or is sick. What is missing in the term “caregiver” is acknowledgement that caring for someone is usually not a one-way street. Both the person receiving care and giving care are sharing something together, whether it is stories or thoughts or personal care. By using the term “care partner,” we level the power in the relationship and acknowledge that both parties have valuable things to give. When people are “care partners,” the relationship is a two-way street of give and take, and giving care is something we all can do.

Need more assistance or want to talk to someone?
These organizations will share local respite options and brainstorm solutions that work for you:

- Colorado Respite Coalition: 303-233-1666
- Seniors’ Resource Center: 303-238-8151
- Colorado Gerontological Society - Senior Answers: 855-293-6911
- Aging & Disability Resources for the Denver metro area: 303-480-6700
- Eldercare Locator (a national hotline for aging resources all over the US): 1-800-677-1116

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